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ABSTRACT

This document presents witness testimonies and prepared statements from the Congressional hearing called to examine the severe health problems of infants whose mothers abused drugs, alcohol, or tobacco during their pregnancies, or who suffer from acquired immunodeficiency syndrome (AIDS). Opening statements are included from Congressmen George Miller and Dan Coats, and from Congresswoman Lindy Boggs. Witnesses include: (1) Elaine B. Arkin, the chairperson of the steering committee, Healthy Mothers, Healthy Babies Coalition; (2) Ira J. Chasnoff, assistant professor of pediatrics and psychiatry at Northwestern University Medical School; (3) Sterling K. Clarren, associate professor of pediatrics, University of Washington School of Medicine; (4) Jennifer Custis, a parent; (5) Lawrence Fenton, professor of pediatrics, University of South Dakota School of Medicine; (6) James S. Marks, assistant director for science, Center for Health Promotion and Education, Centers for Disease Control; (7) James Oleske, director, division of allergy, immunology and infectious disease, University of Medicine and Dentistry of New Jersey; (8) Joyce N. Thomas, director, division of child protection, Children's Hospital National Medical Center; and (9) Benjamin Walker, Jr., chief executive officer, Odyssey Foundation of New York, Inc. Letters and supplemental materials appear throughout the text. (NB)

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PLACING INFANTS AT RISK: PARENTAL ADDICTION AND DISEASE

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HEARING

BEFORE THE

SELECT COMMITTEE ON CHILDREN, YOUTH, AND FAMILIES HOUSE OF REPRESENTATIVES

NINETY-NINTH CONGRESS

SECOND SESSION

HEARING HELD IN WASHINGTON, DC, MAY 21, 1986

Printed for the use of the
Select Committee on Children, Youth, and Families

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PLACING INFANTS AT RISK: PARENTAL ADDICTION AND DISEASE

WEDNESDAY, MAY 21, 1986

HOUSE OF REPRESENTATIVES,
SELECT COMMITTEE ON CHILDREN, YOUTH, AND FAMILIES,
Washington, DC.

The committee met, pursuant to notice, at 9:30 a.m., at Children's Hospital National Medical Center, Washington, DC, Hon. George Miller presiding.

Members present: Representatives Miller, Coats, and Boggs.

Staff present: Ann Rosewater, deputy staff director; Judy Weiss, professional staff; Victoria Doyle, intern; Carol Statuto, minority deputy staff director; and Joan Godley, committee clerk.

Chairman MILLER. The Select Committee on Children, Youth, and Families will come to order.

Since its inception, the Select Committee on Children, Youth, and Families has been dedicated to launching healthy babies, and maintaining healthy families.

Today's hearing, Placing Infants at Risk: Parental Addiction and Disease will focus on a new and extremely disturbing threat to the well-being of babies: The severe health calamities which befall infants whose mothers abuse drugs, alcohol, or tobacco, or who suffer from AIDS.

This is a particularly unsettling period for the American infant.

This year, there were more impoverished children than in almost any year since 1965.

We know from respected sources, ranging from the Institute of Medicine to the Southern Governors Association that in the last 3 years the number of women receiving early prenatal care has decreased. We know for the first time in two decades infant mortality rates are leveling off, and we know that the number of babies perishing between 1 month and 1 year is actually rising.

The result is that we lose more babies in their first year than we lose adults to diabetes, breast cancer, and leukemia combined.

For those infants who survive, we spend billions on the most expensive side of the health care equation, hospitalization costs. It is in this unhealthy context that we are now beginning to see more infants born to drug and alcohol addicts, and to abusers, smokers, and the victims of AIDS.

It is in this context that we see a substantial increase in the number of women using heroin, cocaine, and stimulants, and find 61 percent of all women 20 to 34 drinking, and see the greatest increase in smoking taking place among teenage girls.

Unless these trends are reversed, we can be absolutely certain that there will be more low birthweight infants, who are 20 times more likely to die than the normal weight babies. For those who survive, we know that they will be at a much greater risk of disease and developmental handicaps, like cerebral palsy and mental retardation.

No caring person, and no policymaker, can accept such a future. More than enough evidence exists to show that we can reduce low birthweight, that we can save a great deal of money, and we can give children what is accepted as their American birthright—an equal chance to thrive.

It is in this spirit that we hold today's hearing. We hope to establish the linkage between parental addiction and abuse, and increased infant mortality and morbidity. We want to help educate parents and policymakers, so that both will understand how unnecessary and preventable are some of the worse problems facing our youngest children.

As Dr. Ian MacDonald, the Administrator for Alcohol, Drug Abuse and Mental Health Administration told this committee last year, with regard to future prevention and intervention needs, "I think we are in terrible shape."

I agree with him. It is my hope that today's effort will help us refocus and better understand how to prevent, and treat infants born at risk, due to parental addiction, substance abuse, and smoking.

[Opening statement of Chairman George Miller follows:]

Opening Statement of Hon. George Miller, a Representative in Congress From the State of California and Chairman, Select Committee on Children, Youth, and Families

Since its inception, the Select Committee on Children, Youth, and Families has been dedicated to launching healthy babies, and maintaining healthy families.

Today's hearing, "Placing Infants at Risk: Parental Addiction and Disease," will focus on a new and extremely disturbing threat to their well-being: the severe health calamities which befall infants whose mothers abuse drugs, alcohol or tobacco, or who suffer from AIDS.

This is a particularly unsettled period for the American infant.

This year there were more impoverished children than in almost any year since 1965.

We know, from respected sources ranging from the Institute of Medicine to the Southern Governors' Association, that in the last three years the number of women receiving early prenatal care has decreased; we know that for the first time in two decades infant mortality rates are leveling off; and we know that the number of babies perishing between one month and one year of age is actually rising.

The result is that we lose more babies in their first year than we lose adults to diabetes, breast cancer and leukemia combined.

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I agree with him. It is my hope that today's effort will help us re-focus, and better understand how to prevent, and treat, infants born at risk due to parental addiction, substance abuse and smoking.

PLACING INFANTS AT RISK: PARENTAL ADDICTION AND DISEASE A FACT SHEET

I. OVERVIEW

Parental behavior linked to increased infant risk

Behavioral and environmental risks, such as smoking, alcohol and other substance abuse, are among the "risk factors" which indicate an increased chance, or risk, of bearing a low birthweight infant. Low birthweight is one of the greatest predictors of infant mortality, and also increases the risk of illness. (Institute of Medicine [IOM], Preventing Low Birthweight, 1985).

Most mothers continue to smoke or drink during pregnancy

In 1980, only 18% of smokers stopped smoking during pregnancy, while only 30% of mothers who drank stopped during pregnancy. (National Natality Survey, National Center for Health Statistics [NCHS], 1980).

Of the 50% of high school dropouts (less than 12 years of education) who smoked before pregnancy, only about 10% stopped smoking during pregnancy. Of the 15% of college graduates who smoked before pregnancy, about 24% stopped smoking during pregnancy. (National Natality Survey, NCHS, 1980).

Infants affected by drugs, alcohol, smoking are high cost to society

One Fetal Alcohol Syndrome (FAS) child requires an average of $405,000 in direct special services from birth to age 65. The total costs of FAS to society, including direct services and loss in productivity, are estimated at between $1.937 billion and $9.687 billion, with a median estimate of $3.236 billion. A conservative estimate on the health costs for treating babies born with FAS in 1980 is $14.9 million. (Harwood, Napolitan, 1985).

Of the 228,300 admissions to neonatal intensive care units, about 15,000 (7%) were attributable to effects of maternal smoking—at an annual cost of $175 million. (G. Oster, et al, Institute for the Study of Smoking Behavior and Policy, Kennedy School of Government, Harvard University, unpublished, 1986).

It is estimated, at Children's Hospital National Medical Center, that a low-birthweight baby averages 16 days in the neonatal intensive care unit, at an average cost of $1,500 per day. (G. B. Avery, Childern's Hospital National Medical Center, May, 1986).

Although low birthweight, other infant risks, largely preventable, prevention efforts are lacking

Policymakers and health professionals know enough to intervene more vigorously to reduce the incidence of low birthweight in infants, and among the factors (affecting low birthweight) that can be recognized and dealt with before pregnancy are . . . smoking, moderate to heavy alcohol use, and substance abuse. . . . (IOM, 1985).

Smoking is one of the most important preventable determinants of low brithweight in the U.S. (IOM, 1985).

A review of alcoholism prevention efforts on the federal, state, and local levels found that prevention has ranked lowest among all alcoholism and drug dependence funding priorities established by the U.S. government. (P. E. Nathan, American Psychologist, April, 1983).

II. DRUG ABUSE

More women of childbearing age are using heroin, cocaine, and stimulants

In a 1982 survey, it was estimated that 4.1 million women ages 12 and up used cocaine during the past year (up from a 1979 survey estimate of 3.4 million), while 1.4 million women had used cocaine during the past month. (National Institute on Drug Abuse [NIDA], National Survey on Drug Abuse, 1979, 1982).

In the same survey, it was estimated that 90,000 women ages 18 to 25 used heroin in the past year, an increase of 10,000 users since a 1979 estimate. (NIDA, 1979, 1982).

According to the 1979 survey, an estimated 390,000 women ages 18 to 25 had used stimulants in the past month. The 1982 survey estimated a dramatic increase to 970,000 women stimulant users. (NIDA, 1979, 1982).

High rate of addict births in New York City, San Francisco

In 1983, the New York City Health Department conservatively estimated 884 addict births, a rate of 7.9 per 1,000 live births. This represents an increase from 1966, when 227 addict births were counted—a rate of 1.5 addict births per 1,000 live births. (New York City Department of Health, August, 1984).

In New York City, the proportion of women in the known addict population rose from 14% to 25% between 1986 and 1973. Since then, the proportion of women has remained at between 25% and 30%. (New York City Department of Health, 1973; R. Brotman, et. al, 1985).

In San Francisco County, CA, 1.2% (114) of the 9,562 total births in 1982 had drug- or alcohol-related symptoms. (M. Jessup, "Chemically Dependent Pregnant Women in San Francisco: A Status Report," August 1, 1983).

Infants severely affected by mother's drug use during pregnancy

Infants born to opiate-dependent women frequently have low birthweights. (L.P. Finnegan, Federation of American Societies for Experimental Biology, April 1985)

Neonatal abstinence, which may be severe and persist for as long as 3 months, causes symptoms that can include central nervous system hyperirritability, gastrointestinal dysfunction, respiratory distress, fever, high-pitched cry, . . . uncoordinated sucking an swallowing reflexes, and dehydration. (Finnegan, April, 1985)

PCP-Exposed infants were found to have sudden outbursts of agitation and rapid changes in level of conciousness. (I.J. Chasnoff, et al, 1983)

Infants born to polydrug-addicts tended to be more depressed than those babies born to methadone maintained women. (I.J. Chasnoff, et al, Pediatrics, August, 1982)

Compared to normal and opiate-addicted infants, cocaine-exposed infants are at a significantly higher risk for Sudden Infant Death Syndrome and respiratory abnormalities. (I.J. Chasnoff, et al, abstract submitted to The Society for Pediatric Research, 1986)

Cocaine abuse is associated with a high incidence of prematurity, intrauterine growth retardation, and intrapartum complications. (M.H. Lifschitz et al, Baylor College of Medicine, Houston, TX, 1986)

According to preliminary observations, cocaine-using women have a significantly higher rate of spontaneous abortion. Furthermore, in pregnancies under study, four women had onset of labor with abruptio placentae immediately after intervenous self-injection of cocaine. (I.J. Chasnoff, et al, New England Journal of Medicine, September 12, 1985)

III. AIDS (ACQUIRED IMMUNE DEFICIENCY SYNDROME)

Numbers of pediatric AIDS cases climbing

As of April 28, 1986, 281 cases of AIDS had been reported in children under 13 years of age. 60% are known to have died. Of children diagnosed with AIDS before 1984, 75%–80% have died. The mortality rate for adults with AIDS is 54%. (Centers for Disease Control [CDC], 1986)

It is not known how many children have milder froms of the illness, or how many are infected, but do not show any symptoms. Experts estimate that for every child with full-blown AIDS, 1 to 3 others may be infected. (M. Rogers, CDC, 1986; G. Scott, University of Miami School of Medicine, May, 1986)

Intravenous drug users pass AIDS virus to infants

75% of pediatric cases contracted AIDS from their mother either during pregnancy, or immediately after birth. Of those, 61% of the mothers were drug users themselves, and 12% were the sex partners of men who used drugs. Sixteen percent of children with AIDS contracted it from blood transfusions or blood products. (M. Rogers, CDC 1986)

Not all mothers who test positively for HTLV-3 (the AIDS antibody) will infect their infants in utero. While it is likely that the majority of babies will test positively not all of them will develop symptoms. (G. Scott, 1986)

In one study of 13 mothers who already had babies who tested positively for the AIDS antibody, 65% of their subsequent children were infected. (G. Scott, 1986)

IV. ALCOHOL ABUSE

Women of child bearing age are drinking

61% of women ages 20–34 drank some amount of alcohol in 1983. Of these 35% drank 5 or more drinks per day. (National Health Interview Survey, NCHS, 1983)

More women ages 18–24 drank heavily (5.7%) than women of any other age group. (CDC, 1985)

Fetal alcohol syndrome

Between 3,700 to 7,400 babies were born with Fetal Alcohol Syndrome in 1982. Up to 36,000 newborns each year may be affected by a range of less severe alcohol-related effects (Ouellette, 1983; NCAI)

Eighty percent of children with Fetal Alcohol Syndrome have prenatal and postnatal growth retardation requiring neonatal intensive care, 45% are expected to have mild to moderate mental retardation, and 56% require a series of audiological evaluations in their first year, with annual check-ups and possible corrective surgery. One out of 8 are expected to have a cleft palate requiring a seres of corrective operations. (Harwood, Napolitan, 1985)

Experts estimate that Fetal Alcohol Syndrome ocurs between 1 and 2 per 1,000 live births. Partial expression of FAS occurs in 3 to 5 live births per 1,000. (Ouellette, 1983)

V. SMOKING

More women of child-bearing age are smoking

A higher proportion of women in their child-bearing years—ages 20 to 35—are smoking now than were doing so in the past. (U.S. Office on Smoking and Health, 1985)

According to the 1980 National Natality Survey, 31% of married pregnant women smoked before their pregnancies, an 26% smoked during their pregnancies. (National Natality Survey, NCHS, 1980)

Smoking linked to fetal death, low birthweight, poor infant health

Maternal smoking results in roughly 50,000 fetal deaths and 4,000 infant deaths in the United States each year. (R.T. Ravenholt, "Cell to Organism: Tobacco's Influence on Development," 1985.)

About 36,000—or 15%—of the low-weight babies born in the United States in 1983, were underweight because the mothers smoked during pregnancy. (Oster, et al, 1986)

The relationship of smoking to intrauterine growth retardation is so well established that the term "fetal tobacco syndrome" is now commonly applied to cases in which the mothers who smoke at least five cigarettes daily throughout pregnancy deliver a baby at full term weighing less than 2,500 grams. (C. Hogue, "Smoking and Birth Weight," 1985)

Spontaneous abortion rates are increased by about one-third among smoking mothers, and are doubled for those who are heavy smokers. (Ravenholt, 1985)

Women who smoke more than a pact of cigarettes a day during pregnancy increase the risk of stillbirth and Sudden Infant Death Syndrome by 35%. (National Association of Children's Hospitals and Related Institutions, Inc., 1986)

Preterm births were found to be increased by 60% in women smoking one or more packs a day. (P.H. Shiono, et al, Journal of the American Medical Association, 1986)

Surviving babies of women who smoke heavily during pregnancy do not start gaining weight at the same rate as infants born to nonsmokers until after four months of age. (G.S. Grubb, Family Health International, 1985)

Children under 3 years of age whose mothers smoked during pregnancy were perceived to be in poorer health, and had higher incidences of bed days, chronic conditions, respiratory conditions, and hospitalizations, than children whose mothers did not smoke. (National Health Interview Survey, NCHS, 1981)

Passive smoke inhalation leads to increased respiratory problems for children

Parents who smoke increase their child's chance of developing both lower and upper respiratory tract illnesses during the first year of life. (R.A. Etzel, CDC, 1985)

Non-smoking women who were exposed to tobacco smoke for two or more hours daily at home or at work had twice the risk of having a growth-retarded infant. (M.B. Bracken, 1985)

Chairman **Miller**. I would like now to recognize my ranking minority member, Congressman Dan Coats.

Mr. **Coats**. Thank you, Mr. Chairman, and thanks to the people here at Children's Hospital, who have graciously opened their facilities to us, to allow us a site visit prior to this hearing, and to actually see firsthand, the problems that we are here to talk about today. It was a most instructive site visit, and I want to thank all those who made it possible.

I would also like to welcome the witnesses who have come before the committee today to present their testimony concerning the effects of parental addiction and disease on the newborn.

It is a tragedy to know parents, as I and Chairman Miller have known, who have suffered through the premature birth of a low birthweight baby, who has to be placed in a neonatal intensive care unit. It is also a real tragedy to find loving mothers, fully committed to their unborn children, deliver babies prematurely, with complications.

But how much sadder, to read expert testimony, and to learn of mothers who, simply through lack of education, or lack of caring, commitment, or sacrifice, subject their children to what we have seen here this morning.

Let us look at some facts. There are hundreds of studies linking smoking with low birthweight, increased perinatal and infant morbidity and mortality, infant growth defects, and impaired scholastic ability.

Infants born to mothers who used cocaine during pregnancy had an increased rate of stillbirths and fetal growth impairment.

Fetal alcohol syndrome is a leading cause of congenital brain damage. It is estimated that alcohol is responsible for 10 to 20 percent of the cases of mental retardation.

While there appears to be little data on the relationship between substance abuse and child abuse, there is no question that a relationship exists if one reviews social work records, or court records. In fact, there are a number of court cases that have examined parental addiction as a prima facie criterion of unfitness as a parent, or prenatal abuse.

I look forward to hearing from the witnesses today about prevention activities, treatment models, and public awareness efforts, designed to reduce these preventable tragedies.

I request, Mr. Chairman, that the hearing record be kept open for 2 weeks, so that additional testimony may be included from other witnesses or from other members of the panel who could not be here this morning.

[Opening remarks of Congressman Dan Coats follows:]

Opening Remarks of Congressman Dan Coats, a Representative in Congress From the State of Indiana, and Ranking Minority Member

Mr. Chairman: I would like to welcome the witnesses who have come before the Committee today to present testimony concerning the effects of parental addiction and disease of the newborn. It is a tragedy to know parents, as I have, who have suffered through the premature birth of a low birthweight baby who then is placed in a neonatal intensive care unit. It is a real tragedy when loving mothers, fully committed to their unborn child, deliver babies prematurely, with complications. How much sadder still to read expert testimony and learn of mothers who simply are not loving enough, and caring or have the proper training to make the necessary sacrifices and commitments to their unborn child.

Consider these facts:

There are hundreds of studies linking smoking with low birthweight, increased perinatal and infant morbidity and mortality, infant growth defects, and impaired scholastic ability.

Infants born to mothers who used cocaine during pregnancy had an increased rate of stillbirths and fetal growth impairment.

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MINORITY FACT SHEET—PLACING INFANTS AT RISK: PARENTAL ADDICTION AND DISEASE

HARD DRUGS (HEROIN, METHADONE)

Socio-economic status is a major factor of infant outcome (and development scores), regardless of methadone exposure.

Methadone outcome studies are problematic in that a high percentage of women on methadone use other drugs. (Rosen and Johnson, 1982; Wilson et at, 1981)

"Development Outcome of Children Born to Methadone Maintained Women," Kaltenbach & Finnegan (1984).

For each class of psychoptropic drug and for any given agent, women are almost twice as likely than men to be involved. (Parry, U.S. Health Service, 1968) Polydrug abuse is a special problem, as is the quality of drugs available on the street.

Most of neonatal mortality is related to low birthweight.

The quality of street drugs vary—this leads to repeated episodes of either withdrawal symptoms or unusually high blood concentrations of the drug.

Drug dependent women are prone to other health complications—gonorrhea, herpes, hepatitis, etc.

Early signs of pregnancy are similar to withdrawal symptoms; this can result in increased drug intake.

"Perinatal Aspects of Psychotropic Drug Abuse," Wapner and Finnegan, Perinatal Medicine, 2nd Edition, 1981

The prevalence of psychotropic drug use among women has always been higher than among men, approximating two times that for each class of psychotropic drug use and for any given psychotropic agent. This has been attributed to: a) greater likelihood of a women visiting a physician; b) excessive demands characterizing female social roles; and c) less use of alternative substances, such as alcohol, in coping with emotional stress.

Abuse of multiple drugs is more prevalent in younger people, thus, among women during the child bearing years.

The type and severity of adverse effects of a given drug on the fetus depend on a multitude of factors, including the size and frequency of dose, the route of administration, the state of pregnancy, maternal health and nutritional status, genetic makeup of the mother and fetus, previous obstetrical history, and a myriad of environmental factors—including concomitant exposure to other drugs, smoking status, and perhaps even environmental pollutants.

Drug Dependence In Pregnancy: Clinical Management of Mother and Child, U.S. Department of Health, Education, and Welfare—Alcohol, Drug Abuse, and Mental Health Administration, 1979.

Maternal malnutrition . . . does not entirely account for low birthweight. Smallness is related to a subnormal number of cells rather than a decrease in cell size. This type of growth failure is consistent with a direct effect of a drug or other agent on the fetus . . . therefore it appears than heroin has a direct effect on intrauterine fetal growth.

White teenagers were much younger (less than 16) at first drug use than were black teenagers. Black teenagers became pregnant at younger ages than white teenagers. The younger the drug dependent woman was at first pregnancy, the earlier she left school, leaving her less likely to complete her high school education. Findings show that early childbearing is in fact related to more frequent or repeated pregnancies.

One indication of good parenting skills in the high-risk mother is the concern she shows for the welfare of her infant in utero. This can be measured to some extent by the number of times she attended the prenatal clinic. Women who were younger at the time of first pregnancy and women who were also younger at the time of first drug use had far fewer prenatal clinic examinations than the remainder of the women. Having a parent or sibling who was abusing drugs, alcohol, or both, was no indication of early drug use. However, 43% of the women did report a family drug or alcohol history.

The amount of violence or abuse experienced by drug dependent women, both sexual and non-sexual, far exceeded that reported by comparison groups. The frequency with which this abuse occurs must be considered as factors in the development of the drug abuse pattern.

"Beyond Adolescent Drug Use and Parenthood: Life History Data on Addicted Mothers in Treatment," Finnegan, Kaltenbach, Ehrlich, National Institute of Health, Monograph Series, 1985.

Toxic responses to narcotics may contribute to malnutrition by interfering with the absorption or utilization of ingested nutrients. Absorption abnormalities are common because of high incidences of lesions of the intestine, liver and pancreas; malnutrition is common because of the frequent presence of liver disease.

Multiple births occur in drug addicted women at a greater rate than that seen in the general population.

With more serious complications in infants of drug dependent mothers, the hospital stay is prolonged, producing maternal separation and the possibility of subsequent maternal detachment.

"Pulmonary Problems Encountered by the Infant of the Drug Dependent Mother," Clinics in Chest Medicine, September 1980, Loretta P. Finnegan, M.D.

One of the most important concomitants of the neonatal narcotic abstinence syndrome is interference with the infant's feeding activities, which tend to become frantic and poorly coordinated, so that the newborn infant requires the attention of a skilled member of the nursery staff to assure adequate nutrient intake.

Drug effects in the newborn are highly dependent on variables such as the history of maternal addiction, the mother's narcotic blood level just prior to giving birth, and the maturity of the infant's own metabolic and excretory mechanisms.

"Pediatric Narcotic Abstinence, Effects of Pharmacotherapeutic and Maternal Drug Usage On Nutritive Sucking Behavior," Kron, Litt, Pheonix, and Finnegan, Journal of Pediatrics, Vol, 88, part 1.

ALCOHOL

3% of adult women are either alcoholics or problem drinkers.

FAS is estimated to occur in 2 out of every 1,000 live births, and less severe fetal alcohol effects are seen in 3–5 births per thousand.

There has been a documented increase in rates of miscarriage for mothers who drink.

Factors influencing the severity of the effects include the age of the fetus at time of exposure, as well as the frequency and the intensity of maternal drinking.

"Perinatal Aspects of Psychotropic Drug Abuse," Wapner and Finnegan, Perinatal Medicine, 2nd Edition, 1981.

Of women aged 21–34, 70% were drinkers, 41% were lighter drinkers, 24% were moderate drinkers, and 6% were heavier drinkers. Of women aged 35–49, 72% were labeled drinkers, with 43% lighter drinkers, 20% moderate drinkers, and 9% heavier drinkers.

Women having six or more drinks at least five days a week were significantly more likely to report birth defects in offspring, and failure to become pregnant after trying for at least a year.

Young women drinkers were most likely to report drinking-related behavior problems, symptoms of alcohol dependence, and repeated occasions of getting drunk or having six or more drinks in a day. All the contrasts of young drinkers with other age groups were statistically significant.

Among women drinkers, neither education nor income had clear relationships to drinking-related behavior problems of dependence symptoms, contary to explanations from past research.

Women in four marital and employment subgroups (unmarried, divorced or separated, cohabiting, or unemployed and seeking work) were more likely than women in four other subgroups (widowed, or married working full-time as housewives or part-time or full-time for pay) to report drinking related behavior problems, dependence symptoms, and occasions of extreme consumption and drunkeness.

"Women's Drinking and Drinking Problems: Patterns from a 1981 National Survey," Wilsnack, Wilsnack and Klassen, American Journal of Public Health, November 1984.

CAFFEINE

The fetus is subjected to almost the same concentration of caffeine in the blood as the mother, but caffeine leaves the fetus' system much more slowly.

Caffeine increases risks of prematurity, and of low birthweight.

"Perinatal Aspects of Psychotropic Drug Abuse," Wapner and Finnegan, Perinatal Medicine, 2nd Edition, 1981.

TOBACCO

There are hundreds of studies linking smoking with low birthweight, increased perinatal and infant morbidity and mortality, infant growth defects, and impaired scholastic ability.

Miscarriages are more frequent among women who smoke.

Infants born to mothers who smoke are, on an average, 200 grams lighter than children of non-smokers.

A higher percentage of sudden infant death syndrome mothers smoked both during their pregnancy and after their babies were born. They also smoked a significantly greater number of cigarettes than other mothers.

The increased mortality among children of smokers continues until at least the age of five. Up to the age of 5, the children of smokers are hospitalized more frequently than control children.

Children of non-smoking mothers scored better in 45 of 48 comparisons; the difference was significant in 14. (HEW Smoking and Health: A Report to the Surgeon General, 1979).

"Perinatal Aspects of Psychotropic Drug Abuse," Wapner and Finnegan, *Perinatal Medicine*, 2nd Edition, 1981.

In 1980, the National Center for Health Statistics reported that 29.6% of females 17 and over were smokers. The Surgeon General's Report on Smoking and Health reported that the peak smoking ages for women coincided with childbearing years. There have been 18 toxic agents identified among the gases of cigarette smoke. The decrease in weight is directly related to the number of cigarettes smoked daily.

The increased mortality among children of smokers is reported to continue until at least the age of 5. Smokers' children were found to be hospitalized more frequently than non-smoker's children.

"Smoking and Its Effect on Pregnancy and the Newborn, The At-Risk Infant: Psycho/Socio/Medical Aspects, Loretta Finnegan.

The relationship between maternal smoking and reduced birthweight is independent of all other factors that influence birthweight including race, parity, maternal size, socio-economic status, and sex of child; it is also independent of gestational age. (Meyer, Jonas, and Tonascia "Perinatal events associated with maternal smoking during pregnancy." American Journal of Epidemiology 103(5): 1976.)

If a woman gives up smoking early during pregnancy, her risk of delivering a low birthweight baby approaches that of a non-smoker. (Yerushalmy, J. "The relationship of parents' cigarette smoking to outcome of pregnancy—implications as to the problem of inferring causation from observed associations." American Journal of Epidemiology June 1971.)

Maternal smoking during pregnancy may adversely affect the child's long-term growth, intellectual development, and behavioral characteristics. (U.S. Department of Health, Education, And Welfare Smoking and Health: A Report of the Surgeon General. Department of Health, Education, and Welfare, Public Health Service, 1979.)

The risk of spontaneous abortion, fetal death, and neonatal death increases directly with increasing levels of maternal smoking during pregnancy. (Meyer, Tonascia, and Buck, "The interrelationship of maternal smoking and increased perinatal mortality with other risk factors." American Journal of Epidemiology 1975.)

An infant's risk of developing the "sudden infant death syndrome" is increased by maternal smoking during pregnancy. (Lewak, Van Den Berg, Beckwith, "Sudden infant death syndrome risk factors." Clinical Pediatrics July 1979.)

Infants and children born to smoking mothers may experience more long-term morbidity than those born to non-smoking mothers; however, studies usually cannot distinguish between the effects of smoking during pregnancy and the effects of the infant's or child's passive exposure to cigarette smoke after birth. (Colley, Holland, and Corkhill, "Influence of passive smoking and parental phlegm on pneumonia and bronchitis of early childhood." Lancet 1978)

Studies in women and men suggest that cigarette smoking may impair fertility. (Persky, O'Brien, Fine, Howard, Kahn, and Beck. "The effect of alcohol and smoking on testicular function and agression in chronic alcoholics," American Journal of Psychiatry 134 1977.)

Birthweights under 2,500 grams were 49 per thousand for non-smokers, 76 per thousand for smokers of less than a pack per day, and 114 per thousand for smokers of a pack per day or more. The risk of having a low birthweight baby therefore increased 53% and 130% for light and heavy smokers, respectively, compared with non-smokers.

Smokers' babies are smaller than corresponding non-smokers' babies in all dimensions measured, including length, head circumference, chest circumference, and shoulder circumference.

Associations have been noted between maternal smoking and deficiencies in neurological and intellectual development of the child.

Smokers' children had lower scores on the majority of tests of intelligence and intellectual function at ages 4 and 7.

Smoking during pregnancy is an important cause of the hyperkinetic syndrome.

Smokers' infants tend towards "irritability, decreased ability for self-control, and a general lack of interest, whereas non-smokers' infants tended to be less irritable and better oriented."

HERPES

Herpes genital infection is not a reportable disease in the United States. However, scientists estimate the incidence of herpes infection by sampling several clinics and have found that approximately one case of herpes infection is diagnosed for every ten cases of gonorrhea. The estimated number of new cases of herpes is approximately 300,000 per year.

Women who have herpes genital infection have as much as three times higher rate of spontaneous miscarriage. Herpes infection increases the risk for premature delivery.

Herpes simplex virus can cause severe disease in infected infants. If a mother is infected at 32 weeks gestation or later, there is an approximate 10 to 20% chance that her infant will be infected; this risk is greatest if the infant is exposed to active infection in the mother's birth canal during delivery.

"Herpes Genital Infection," U.S. Department of Health and Human Services, Public Health Service, Center for Disease Control, 1980.

GENERAL

In current studies, data collection is a problem because of subject attrition—those mothers who would be likely to participate in studies, over continued time periods, may not be representative—"self select samples."

There are no longitudinal studies on these infants—this is simply because studies can't be done faster than the children themselves mature.

Women who use drugs would probably be more likely to neglect normal prenatal care. This leads to a pre-disposition to medical complications in pregnancy.

"Developmental Outcome of Children Born To Methadone Maintained Women," Kaltenbach & Finnegan (1984).

A study of pregnant adolescents revealed that 3% were using heroin or methadone, 8% barbituates or other depressants, 10% marijuana, 50% cigarettes, and 25% alcoholic beverages.

"The philosophy of the Family Center is that drug addiction has an impact not only on the woman, but on the entire family."

Goals: 1) developing personal resources; 2) improving family and interpersonal relationships; 3) reducing/eliminating socially destructive behavior; and 4) facilitating maximum attainable adaptation as new parents.

Mother-infant attachment should be encouraged prenatally and post-partum. Special emphasis should be placed on enhancing parenting skills in an effort to lessen the possibility of child neglect. The mother's ability to care for her infant after discharge from the hospital must be assessed by frequent observations in the clinic and home setting. Long term follow up care is extremely important.

"Family Center," Jefferson Alumni Bulletin, Winter 1985, Loretta P. Finnnegan, M.D.

In the U.S., one in four individuals addicted to narcotics and one in two abusers of alcohol or barbituates are women. The vast majority of women who abuse drugs or alcohol are of child bearing age.

"Pulmonary Problems Encountered by the Infant of the Drug Dependent Mother," Clinics in Chest Medicine, September 1980, Loretta P. Finnegan, M.D.

Chairman. **Miller**. Certainly, without objection, that will be done. I would like now to recognize Congresswoman Lindy Boggs.

Mrs. **Boggs**. We are privileged to be here this morning to be here under the auspices of this great hospital, and its offices and its personnel. And we are privileged to be able to meet with the patients—with the children, with the parents, and with all of the people who are working so very hard, and with such great compassion, in the fields in which this committee is so interested.

I am especially pleased to be here as a former congressional wife, because the Congressional Wives' Club is very active in promoting the programs of Children's Hospital—and with very good cause.

I am also grateful to the witnesses who have come from afar. I am especially pleased that Mr. Walker is here. I have been on the Board of Odyssey House since its inception in my district, and I will be especially interested in his testimony.

Thank all of you for coming. Thank you for your continuing interest, and for the renewed spirit of service that I am certain that you will be dedicated to, following the testimony of these hearings.

Chairman **Miller**. Thank you. Let me also thank, on behalf of the committee, the Children's Hospital for all of the help that they have given us with this morning's hearings, and with the tour. And also with the help that they have given us throughout the life of the select committee, in helping us produce both the evidence we think the select committee needs on behalf of healthy babies and healthy families, and witnesses, and just a tremendous support system for the select committee.

We will begin today with our first panel, which will be Dr. Ira Chasnoff, who is the assistant professor of pediatrics and psychiatry at Northwestern Medical School; Dr. James Oleske, who is the director of the division of allergy, immunology and infectious disease at the University of Medicine and Dentistry of New Jersey; Benjamin Walker who is the chief executive officer of Odyssey Foundation in New York; and Joyce Thomas, the director of the division of child protection for Children's Hospital National Medical Center, here in Washington. If they would come forward please, and we will take your testimony in the order in which I called your name.

Your written statements will be included in the record in their entirety, and you may proceed in the manner in which you are the most comfortable, and which you think will be most helpful to the members of the select committee.

Mr. Chasnoff, we will start with you.

STATEMENT OF DR. IRA J. CHASNOFF, ASSISTANT PROFESSOR OF PEDIATRICS AND PSYCHIATRY, NORTHWESTERN UNIVERSITY MEDICAL SCHOOL, CHICAGO, IL

Dr. CHASNOFF. Thank you for your invitation to address you today.

As we watch children grow, we can select out those children who are at very high risk for problems in developmental and medical outcome. But the factors that place these children at risk can often be identified long before the children are born.

They come from families at risk.

One factor that certainly places a family at risk is under discussion today: drug use during pregnancy.

Patterns of maternal drug use during pregnancy have not really changed since the early 1970's. The use of marijuana, PCP, heroin, alcohol, cigarettes, has changed very little, in fact. Currently about 25 percent of all pregnancies are complicated by at least one of these factors.

However, there has been one significant change in the last few years, and that is the increasing use of cocaine by pregnant women.

The Perinatal Center for Chemical Dependence at Northwestern University, in Chicago, was instituted about 10 years ago to deal with the problems that these drug-exposed infants exhibited.

An infant born to a drug-addicted mother would come into the hospital, be delivered, and spend 4 to 6 weeks in the intensive care nursery, at a cost, very minimally, of about $28,000 per child. Since the institution of our program, which is a comprehensive program to provide medical and psychotherapeutic care for these women before delivery, the average stay of these infants now is 2 to 3 days, at a cost of about $300.

Thus, the costs that were being borne by the hospital and by the insurance companies, and by the State have been cut most markedly.

The recent numbers that we hear about cocaine use in the United States are reflected in pregnant women also. Currently, it is estimated that about 25 million adults are using cocaine, 10 million of them using regularly. In some parts of the country, it is estimated that 10 percent of all pregnancies are complicated by cocaine use.

We know that cocaine does cross the placenta. There have been many instances in which we have had a woman come into the hospital, who has used cocaine just previously, and we can take ultrasound pictures of the infant, and watch the infant jumping around in utero.

We also have been able to find cocaine levels in the blood and urine of infants for several days after birth, if the mother has used cocaine in the last few days before delivery.

Complications of pregnancy that we have seen in our program include a high rate of spontaneous abortion in the first part of pregnancy; a high rate of stillbirths due to abruptio placentae—that is, when the placenta separates from the walls of the uterus prematurely; poor growth of the child in utero; and inability of the child to respond or interact with the human environment, once he is born.

We have also had two infants, who have had a stroke in utero from their mothers' cocaine use.

This has been reported in adults who use cocaine, but there have been no previous reports in infants born to cocaine-using mothers.

Recently, we have also been investigating the high rate of sudden infant death of these infants.

In the general population in Cook County, IL, there is a rate of sudden infant death of three-tenths of 1 percent. Among heroin users' infants, the rate of sudden infant death is 4 percent. In this study that we just completed, the rate of sudden infant death for cocaine-exposed infants is 15 percent. So, you can see that there is a markedly increased rate of sudden infant death.

This was a retrospective study, and we are in the process, of looking at this problem over a long-term basis to confirm these facts, but it gives us an idea that cocaine does have effects long after pregnancy is over.

As we evaluate these children over the long term, we cannot examine these children only in the context of their exposure to drugs. It would be very convenient if we could predict that any child exposed to drugs in pregnancy would fail to develop normally, or would have medical problems in future years.

But this is an oversimplification. It would fit a very nice medical model, that said drug use causes problems, and it would give us a rationale for treatment; that is, keep pregnant women off of drugs.

But it is not simply a matter of drug use. The issues are very complex, and the quality of parenting that each child receives from his parents is more a factor in the long-term outcome of these infants than their actual exposure to drugs.

Thus our role is not only to educate the public as to the dangers of drug use in pregnancy, but to address issues that engender and enhance the effects of drug use: poverty, malnourishment, ignorance, and immaturity on the part of the parents.

It it is not a problem of only numbers. The interactional effects that produce the addictive personality in the first place must be understood, and this personality must be changed, or at least intervention must be instituted, before success can occur on behalf of these very innocent bystanders in the process of addiction, the children about whom we are talking today.

Thank you.

[Prepared statement of Dr. Ira Chasnoff follows:]

Prepared Statement of Ira J. Chasnoff, M.D., Assistant Professor of Pediatrics and Psychiatry, Northwestern University Medical School, Director, the Perinatal Center for Chemical Dependence, Northwestern Memorial Hospital, Chicago, IL

BACKGROUND

As our sophistication in defining the problems of drug abuse has increased, awareness has increased regarding unique populations within the large group of substance abusers who require further study and specialized types of treatment. One such population is the pregnant substance abuser and her offspring. At the present time, most information is concentrated on the effects of alcohol and opiates on pregnancy and the neonate. However, with the increasing use of cocaine in the United States, there has been growing concern regarding the effects of cocaine on the fetus and neonate of the pregnant abuser.

Data on women of childbearing age show that they are "represented or overrepresented among those persons who are current and regular users of legal drugs, illegal drugs and alcohol" (Chambers and Hart, 1977). More specifically, studies looking at drug use by women during pregnancy (Forfar and Nelson, 1973; Hill, 1973; Doering and Stewart , 1978; Kaul et al., 1978) have shown that 63-93.5% used analgesics during pregnancy (these were not broken down to differentiate narcotic from nonnarcotic analgesics), and sedative drug use ranged from 22-28%. The majority of the women involved in these studies were women who were receiving prenatal care and were obtaining these medications by prescription from their physicians. Jacoby (1975), in a study of 86 pregnant women from a lower socioeconomic level than the women in the previously mentioned studies, found that by checking urines using thin-layer chromatography, 22% had barbiturates, salicylates or quinine in their urine. This high level of drug use during pregnancy may often coincide with concomitant alcohol use or the alcohol use may exist without drug use. With an estimated 20 million Americans having tried cocaine at least once, and 5 million using it on a regular basis (Fishburne, 1980), it can be assumed that cocaine follows the same pattern of use as the previously mentioned substances, and large numbers of pregnant women have used cocaine.

It is erroneously believed by many women that the placenta acts as a barrier protecting the fetus from various toxic substances taken by the mother during pregnancy. However, this is not so. Numerous reviews of drug use during pregnancy show that the placenta is freely crossed by many drugs taken by the mother during pregnancy (Goldstein et al., 1974; Mirkin, 1975; Finnegan, 1976; Hollingsworth, 1977; Yaffee, 1978). Drugs which act on the central nervous system are usually lipophilic and are of relatively low molecular weight (less than 1000), characteristics that facilitate the crossing of the blood-brain barrier. These are the same characteristics which facilitate crossing the placenta from maternal to fetal circulation. For many sedative-hypnotic medications, there is rapid equilibration of free drug between the maternal and fetal circulation. Although the exact distribution of drug between maternal and fetal circulation is difficult to determine because of a large number of variables (Mirkin, 1973), it is reasonable to say that drugs with high abuse potential (opiates, cocaine, sedative-hypnotics, alcohol and stimulants) are found at significant levels in the fetus if the mother is using or abusing these drugs. Some drugs which accumulate in the fetus can be metabolized by the fetal liver and the placenta. Frequently, the metabolites are water-soluble, which hinders the passage of the metabolite back across the placenta to the maternal circulation where it can be excreted.

Because the fetal liver is not fully developed, it is frequently difficult to anticipate the exact fate of a specific drug in the fetus. Rane and Tomson (1980), in a recent review of prenatal and neonatal drug metabolism, indicate that the majority of drugs studied have a longer half-life in the fetus than in the adult. This is also true in the neonate since the enzymes involved in the metabolic process of glucuronidation and oxidation are not fully developed in the fetus. In addition, the immature renal function of the newborn may delay the excretion of drugs which have been metabolized to an excretable form.

The fact that drugs cross the placenta and reach the fetus creates potential for problems of fetal development. These problems can be manifested as congenital abnormalities, fetal growth retardation, low birth weight, neonatal growth retardation or behavioral problems. Intrauterine growth retardation is the major adverse effect of drugs taken in the second and third trimesters, whereas congential abnormalities are the major adverse effects of drugs taken in the first trimester of pregnancy (Redmond, 1979).

Besides intrauterine growth retardation and congenital abnormalities, one of the important effects of maternal drug use during pregnancy, especially use of drugs with high potential for abuse, is that dependence develops in the fetus as well as the mother. The extensive literature on opiate addiction during pregnancy has been reviewed in the NIDA publication Drug Dependence in Pregnancy: Clinical Management of Mother and Child (1979). Since the fetus develops tolerance and dependence, it will experience withdrawal when the mother is withdrawn from her drug or at term when the maternal drug use no longer provides the newborn with drugs. Besides withdrawal from opiates, withdrawal syndromes in the newborn have been described with secobarbital (Bleyer and Marshall, 1972); ethchlorvynol (Rumack and Walravens, 1973); phenobarbital (Desmond et al., 1972; Blumenthal and Lindsay, 1977); diazepam (Rementeria and Bhatt, 1977; Backes and Cordero, 1980); chlordiazepoxide (Athinaravanan et al., 1976), glutethemide (Reveri et al., 1977); lorazepam (de la Fuente et al., 1980) and alcohol (Schaefer, 1962; Nicols, 1967).

The predominant literature on perinatal addiction focuses on the problems of alcohol and opiate addiction. The literature on opiate dependence in pregnancy and neonatal complications has been reviewed in a book edited by Rementeria (1977); the NIDA monograph Drug Dependence in Pregnancy: Clinical Management of Mother and Child (1979) and in several recent articles (Eriksson et al., 1979; Glass and Evans, 1979; Hill and Stern, 1979). All that is mentioned about drugs other than opiates is the presence of withdrawal syndromes in the newborn, the potential for low birth weight and the possible teratogenic effects. There is limited information regarding the effects of stimulants during pregnancy, with no information regarding cocaine's effects on fetal development or neonatal neurobehavior.

A recent study completed in our program (Chasnoff et al., 1982) showed that infants born to polydrug-addicted mothers differed from babies born to opiate-addicted mothers and drug-free controls. The opiate-addicted babies were smaller than the polydrug-addicted babies and the controls and had smaller head circumferences. On the Brazelton Scale, the opiate-dependent group had more depression of interactive behaviors and state control than the polydrug group, although the polydrug group had more depression in these scales than controls. (See paper in Appendix for summaries of data.) Although the polydrug group was heterogeneous, it indicates that there is impairment in neonatal development in infants born to mothers who abuse drugs other than narcotics. Despite the fact that in our experience and the experience of most treatment programs patients are abusing more than one class of drug, there is little data on the effects of nonnarcotics on pregnancy and subsequent neonatal development. Chambers and Hart (1977) state that "too little attention has been given to those pregnant women who are high frequency users of drugs other than heroin. There is no question among drug abuse epidemiologists that this group of women whose primary drug is not heroin far exceeds the number who are addicted to narcotics.

PRELIMINARY STUDY

Although it would be anticipated that cocaine would cross the placenta, recent data from our clinic confirms this in two infants born to mothers who had snorted cocaine just prior to delivery. The infants excreted unchanged cocaine at 12 to 24 hours post delivery and continued to excrete benzoylecgonine, a cocaine metabolite, for five days. There are conflicting reports of cocaine's teratogenicity in animal studies (Mahalik et al., 1980; Fantel and Macphail, 1982), and the effects of cocaine on pregnancy in the human have not been previously studied. A report of two cases of abruptio placentae associated with cocaine use appeared in 1983 (Acker et al.), but no further evidence for this association had been published since. In a preliminary study in our program (Chasnoff et al.,1985) 23 infants were born between June 1983 and September 1984 to cocaine-using women enrolled in the Perinatal Center for Chemical Dependence of Northwestern University Northwestern Memorial Hospital. All of the women were enrolled by the second trimester of pregnancy and had completed a course of intensive prenatal care. Maternal urine samples and breathalyzer tests were obtained on a regular basis in order to screen for illicit drug and/or alcohol use. In order to specifically evaluate the effects of cocaine on pregnancy and the newborn, the cocaine-using women were divided into two groups based on concurrent use or nonuse of narcotics and were compared to two control groups. One control group was selected from the population of the Perinatal Center representing methadone-maintained patients who did not abuse cocaine, and the other control group was selected from nonaddicted pregnant women presenting for prenatal care at the Prentice Ambulatory Care Clinic. Both control groups were matched for maternal age, gravidity and cigarette, marijuana and alcohol use.

It was found that infants born to mothers who used cocaine during pregnancy had an increased rate of stillbirth due to abruptio placentae and impairment of their growth in-utero. These infants also showed a deficiency in their ability to interact with and respond to their mothers, a characteristic that hampers proper bonding between the newborn and its mother. Further studies by our group have also shown an increased incidence of sudden infant death syndrome ("crib death") in infants born to mothers who use cocaine. Much further information on the effects of cocaine on the developing fetus, newborn and child is needed before direct correlations between use and abnormalities in the newborn can be drawn.

FUTURE DIRECTIONS

From the information above it can be seen that there is no question that the use and abuse of drugs during pregnancy is a critical problem in the United States. The toll in human cost is unestimable, but from a purely economic viewpoint intensive educational and therapy programs save large sums of money for hospitals and medical facilities. At Northwestern Memorial Hospital, prior to the institution of our program, the Perinatal Center for Chemical Dependence, in 1976, the average hospital stay for an infant born to a drug dependent woman was 4 to 6 weeks. At approximately $1000 per day for intensive care of the infant over that period of time, the most conservative estimate of cost to the hospital, the insurance company or the state would be $28,000. Since institution of the program, the average period of hospitalization for the infants is 2 to 3 days in the regular newborn nursery, a maximum cost of $300 to $400. There is no question that adequate and appropriate prenatal care is a requisite for pregnant substance abusing women.

Long-term evaluation of these infants will also be necessary in order to intervene when necessary. It would be convenient if we could simply predict that any child whose physical system has been affected by his mother's chemical dependence would fail to respond appropriately or demonstrate deficiencies in particular areas of development. However, this would be a vast oversimplification of the problem of substance abuse and its effects on both the infant and the mother. This oversimplification would fit a purely medical model, that is, a straightforward cause and effect pattern. This would provide a rationale for preventive medicine: keep pregnant women off drugs. But the quality of parenting shown by human mothers and fathers varies greatly, from comfortable, confident parents at one end of the spectrum to anxious, depressed or even abusing parents at the other end. It is this quality of parenting that is going to be the key to the approach to the problems facing educators and medical personnel in this field. We must not only educate the public as to the dangers of drug use in pregnancy, but we must address issues that engender and enhance drug abuse: ignorance, poverty, malnourishment, immaturity.

It is not simply a problem of numbers of drug users. The issues are complex, and the interactional effects that produce the addictive personality in the first place must be understood and interrupted before successful intervention can be undertaken in behalf of these innocent bystanders in the process of addiction, the children.

Chairman MILLER. Thank you. Dr. Oleske.

STATEMENT OF DR. JAMES OLESKE, DIRECTOR, DIVISION OF ALLERGY, IMMUNOLOGY AND INFECTIOUS DISEASE, UNIVERSITY OF MEDICINE AND DENTISTRY OF NEW JERSEY, NEWARK, NJ

Dr. OLESKE. In 1972, as part of my masters in public health requirements, I looked at 118 infants born to drug-using women in Newark, NJ. And I remember, after finishing that study, coming away from it, saying that these children never could have had it worse. There were so many complications, so many problems compared to a normal infant, born into the same socioeconomic status as these, except their mothers did not use drugs.

In 1979, unfortunately, 8 years later, we began to notice a new disease that seemed to be occurring in children as it was occurring in adults at that time. That disease is now very well-known as AIDS. And it was devastating to find out that the same group of children who had so many problems because their parents used drugs, now were subjected to another tragedy. And that is the risk of developing Acquired Immune Deficiency Syndrome.

That problem has mushroomed. In the United States right now, there are probably 1,000 to 2,000 infants with AIDS. In Newark, NJ alone, we have cared for 90. Almost half of those have died.

The vast majority of infants who have AIDS are born to women who are either drug users themselves, or had sexual contacts with a male who is a drug user, or in one of the high-risk groups such as bisexuals.

Fortunately, the acquisition of AIDS into newborns because of blood transfusion, with the new screening tests, has become less of a problem.

So, clearly, the problem of AIDS in children and the problem of AIDS facing society, is mostly derived from the drug-using populations, and particularly children born to such women.

The CDC has had 350 cases reported to it of pediatric AIDS, but as I mentioned, clearly this represents significant underreporting. And as I mentioned, there is potentially 2,000 cases right now in the United States of pediatric AIDS.

The mortality rate, overall, in this group of children is 45 percent. The clinical presentation has been well-documented. These children have failure to thrive. They have a special type of pneumonia. They have chronic diarrhea, swollen lymph glands, swollen liver and spleen. And most devastating, the recognition that maybe half or more have an encephalopathy. In other words, their brains are directly infected. And this, of course, introduces so many problems, as it relates to treatment and rehabilitation.

Their immune system is depressed, just like the adults, and they are at the risk of many opportunistic infections, many of them difficult to treat.

The treatment programs that are available are catch-as-catch-can. They have been developed in places where the concentration of patients are most heavy. They have developed without support. Presently, we only give supportive care to children. We work on nutrition, we work very hard on it, because we recognize it as one of the major problems.

We treat all their ongoing infections, which are many. We use special drugs for special situations. In particular, we use intravenous gamma globulin, a very expensive therapy, for these children to try to prevent infection. The cost of these sometimes are rejected and denied by the various health care providers.

Specific therapy programs for children are still not available. We try to provide rehabilitation services, because of the tremendous problems these children have, as I mentioned, related both to their encephalopathy, and also their deprived background.

There are tremendous needs for psychosocial services to these groups. The parents need help. The children need help.

It is sad that these children are born to a family that is fractured, has little ability to care for the child. Twenty-eight percent of our mothers are dying of AIDS themselves, and trying to take care of a child who is dying of AIDS.

There are problems of schooling, that I will not even begin to get involved with at this point. But clearly, one of the things we have learned is not every child, or for that matter, adult with AIDS is going to die. Some of them, if we give them good support and good care, may survive. And they are going to go to the schools, and they are going to survive, and they are going to be interwoven back into society. And we are going to have to accept them. And we are going to have to figure out how to do that.

Right now, hysteria reigns, and unfortunately, we have no rational approach to this. The four States that have examined the issue of children going to school, fortunately have all said that these children could go to school. Unfortunately, of all the States that have considered it, the local school boards have rejected that decision.

Adoptive services are a problem. Originally, these children are born into families where adoption and foster care is frequently necessary. It is an added difficulty in providing foster care service and adoptive services for these children.

Frequently, the parents of these children and the foster care families are overwhelmed, and we need to provide respite care for these patients. None of this is really available.

In conclusion, really, I guess I have to say that we need comprehensive programs for this group of patients. Those with AIDS and born into the drug-using family.

These programs need to be comprehensive, need to take into consideration both the medical issues and the psychosocial issues which are presently overwhelming.

I might point out that presently, there is little or no funding for these issues. Children receive very, very little of the moneys allocated to AIDS work. Most of the money goes to research. Very, very little for care and treatment.

As one of the major centers for pediatric AIDS in the United States, we have not received any Federal dollars for the care of patients with AIDS. It all has been, if you will, a local effort.

Pediatricians, and people taking care of children, have always been, or tried to be, the spokesmen for these silent victims of society's mishaps. Clearly, we are trying to speak out, but clearly, I do not think we are being heard very often.

These children need tremendous numbers of helps. We are not having movie stars giving benefits for children born to drug users. And we probably should not rely on those efforts.

We should rely on the Federal Government for their efforts to take care of these children. These children deserve good care, and they are not getting good care, because of the limited resources available to this tragic group of patients.

Thank you.

[Prepared statement of Dr. James Oleske follows:]

PREPARED STATEMENT OF DR. JAMES OLESKE, CHILDREN'S HOSPITAL OF NEW JERSEY

Since 1981, Children's Hospital of New Jersey has provided care to children with HTLV-III infection (AIDS). The average age at diagnosis is 6 months, and the majority of patients are toddlers and preschool aged children. Of 41 children actively followed, most have multiple problelms including poor weight gain, developmental delays, vision defects and speech deficits. Many families have a history of impaired parenting skills, intravenous drug abuse, and adult AIDS. In addition, parents and guardians are stressed due to recurrent and chronic infections, the uncertain outcome of the disease and the social isolation that can result when the child is diagnosed as having AIDS.

The majority of children with AIDS in New Jersey receive treatment at Children's Hospital. The program is coordinated by a pediatric nurse practitioner/clinical specialist who has overall responsibility for the organization and implementation of service to children and their families. She also initiates assessment by other services and provides on-going case management in both acute and ambulatory care settings.

The "AIDS team" sees every child monthly and more frequently if warrented by the child's condition. At the monthly visit, the child is seen by the various team members. Disciplines represented at the clinic include medicine, nursing, social work, nutritionist, speech therapy, occupational therapy. The following protocol has been developed for the management of the well child with HTLV-III infection:

- interval history and examination
- neurologic evaluation
- evaluation of the home environment/consultation with services involved in the case
- assessment of parental coping
- developmental review and home program (speech pathologist and occupational therapist)
- comprehensive evaluation by the Child Development Center every 6 months

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Staff members are well known throughout the state and the nation as experts in the care of children with AIDS called upon to act as resources for physicians, nurses and other health care professionals. The staff is actively involved in educational and advocacy issues related to pediatric AIDS. Upon recognizing the need for service for developmental delays and the resistance of community programs to accept children with AIDS, we sought and obtained funding from the Department of Education for an Early Intervention Program. In operation since January 1986, it can provide rehabilitation services on a once a week basis for up to 12 children.

The present program developed informally in response to the needs of the children/families receiving care at Childrens. The high incidence of AIDS in northern New Jersey, particularly Essex and Hudson counties, and the existence of a multidisciplinary program at Children's Hospital supports the formal designation of CHAP as the state center for the diagnosis and treatment of pediatric AIDS. Support and funding are needed to formalize the existing program and expand services. In addition, a defined physical space must be found for staff, equipment and the provision of direct care to the patients on a daily basis. We have identified the following areas for development:

1. Volunteer support. Several groups have approached us to collaborate on a community network of volunteers for children. At this point, staff do not have the necessary time to work with these groups.
2. Educational materials. There is a great need for educational materials on AIDS for children, parents, schools and community. We have recently written a guide for parents and have expertise to develop other materials.
3. Resource/consultation. We are receiving an increasing number of requests for information on the needs of children and the specifics of developing a comprehensive treatment program. We are looked upon as a model program nationally and internationally. We would like to have the personnel to func ton as a resource to others.
4. Jersey City. We would like to develop a satelite ambulatory facility in Jersey City for non acute care. Children would continue to be hospitalized at Children's but routine treatment could occur closer to home.

At this time, we seek support for the following positions:

1. CHAP coordinator/case manager (masters prepared nurse) for program planning and implementation.
2. Staff nurse (Registered nurse) to assit in day to day operations.
3. Community health nurse (Bachelors prepared nurse) Full time to make home visits on an acute and elective basis. She would also coordinate hospital to home care and deal with home care agencies.
4. Social worker (masters prepared) to provide counseling and support to children and families. The social worker would also supervise volunteers and work closely with schools, DYFS, and other community agencies.
5. Secretary to provide support to the above staff.
6. Clerk to assit with routine record keeping related to patient care.
7. Jersey City would require an additional case manager (masters prepared nurse) and social worker (masters prepared). Clerical support and space would also need to be identified.

The above is a brief overview of the health and psychosocial problems of the child with AIDS and the attempts of Children's Hospital to meet those needs. Although we have developed a strong clinical program, additional support is needed if we are to continue to provide care as well as ongoing data collection, research and education.

We also see a need for an out of hospital facility (group home or some version of) to provide a temporary home for children awaiting placement in foster care and/or confirmation of diagnosis. This same facility should also be available to provide respite care when parents need a break or if a parent (with AIDS) is hospitalized and the child needs a place to stay.

James Oleske, M.D.
Edward Connor, M.D.
Mary Boland, R.N., MSN

CHILDREN'S HOSPITAL AIDS PROGRAM (CHAP)

Number of children with AIDS/ARC since 1981	80
Number of children presently treated	42
Number of children lost to follow-up	0

Out-patient visits per child	1-2/month
Hospitalizations per child	2-3/annually

Concurrent problems identified in these children

- failure to thrive
- encephalopathy
- developmental delays
- speech and hearing deficits
- nutritional deficits
- family/social problems
- recurrent fever
- acute and chronic infections

Departments involved in treatment (ambulatory and acute)

Division of Pediatric Immunology and Infectious Diseases
Division of Pediatric Neurology
Division of Pediatric Pathology
Division of Pediatric Hematology
Division of Pediatric Gastroenterology
Division of Pediatric Nursing
Department of Habilitation
Department of Speech and Hearing
Nutritionist
Early Intervention Program
Child Development Center

CHILDREN'S HOSPITAL AIDS PROGRAM (CHAP)

PROFILE OF 36 CHILDREN WITH HTLV-III INFECTION*

Age		
Age	0 - 12 months	8
	13 - 24 months	6
	2 - 4 years	13
	4 - 6 years	8
	6 - 13 years	1

Number of Children Requiring:

Foster care placement	14
Community nursing service	14
Family protective agency	13

	ARC	AIDS	TOTAL
Height at or below 10%ile	12	12	24
Weight at or below 10%ile	13	13	26
Developmental Delay	12	14	26
Encephalopathy**	7	11	18
Interstitial Pneumonitis	-	12	12
Surviving	17	9	26

* Data as of January 31, 1986

**Encephalopathy is defined as abnormal findings on neurological exam and/or abnormal CAT scan

Chairman MILLER. Thank you.

This panel has been joined by another one of our witnesses, Jennifer Custis, who is a parent from Vienna, VA, who is accompanied by Meredith Finsterbusch, who is a program coordinator at the women's center.

Jennifer, are you ready to testify?

Ms. CUSTIS. Yes.

Chairman MILLER. All right.

STATEMENT OF JENNIFER CUSTIS, PARENT, VIENNA, VA

Ms. CUSTIS. I am going to go ahead and read this.

Chairman MILLER. Proceed in the way in which you are the most comfortable. We are a very relaxed committee.

Ms. CUSTIS. Thank you. My name is Jenny, and I am 28 years old, and I am a recovering alcoholic and drug abuser.

When I was 5, my mother and father split up. My brother and I were left with my mother, who eventually turned to prescription drugs, such as valium, to ease her pains. We all moved in with my grandmother, and there were many conflicts and hardships. My childhood was nowhere close to being normal.

My mother died when I was 16, from emphysema and drug abuse. Between the anger I had with God, for taking away my mother, and the kids who teased me unmercifully at the time, for being a goody-goody, I turned to tequila and marijuana. I wanted to ease the pain, and I wanted to fit in with the crowd.

When I was 18, I moved in with, who is now my ex-husband, who is also an alcoholic. I was 20 when I got pregnant with our first child.

I quit drinking within the first 3 months of my pregnancy, because it made me sick. I continued to smoke pot once in a while.

I got prenatal care as soon as possible, but lied to my doctors about the occasional joint I smoked.

My son was carried full term, weighed 7 pounds 11 ounces, and there were no complications.

A little over a year later, I gave birth to my daughter. During my pregnancy, I smoked pot and drank for the first 3 months. I did not know I was pregnant at the time. The pot and the booze started making me sick, so I quit, and started getting my prenatal care at that time, also.

I tried to get high a few times, in spite of the fact that it made me sick. My daughter was carried full term, weigh 6 pounds, 12 ounces, and there were no complications.

Three years later, and many hardships later, I got pregnant with my third child. By this time, I was drinking very heavily due to stress. I drank and smoked pot the whole time I carried him. It never once made me sick. I started questioning my drinking and drugging at this time, and my friends would tell me that they never had anything go wrong with their pregnancies over it, so I figured it would not happen to me.

My son was born 7 weeks prematurely. My water broke, and he went into distress. And the doctors had to take him by C-section. He weighed 3 pounds, 14 ounces. I only had been getting prenatal care a very short time prior to this, because I did not want anyone to find out I was sick. He is doing fine now, but he had some problem with muscle development.

I ended up giving up my children just a few weeks after I brought my new baby home, because we could not afford to keep a roof over our heads. This gave me a chance to leave my ex-husband, and left me plenty of free time to drown in my sorrows. The pain I felt cannot be measured in any way.

In spite of the alcohol and drug increase, I got a job and I kept it. I had a roof over my head, I gained weight, and eventually convinced everybody I was straight. Never had a drinking and drugging problem. And I became more secure than I had ever been at any point in my life.

I was also doing over the counter speed at this time, so I could make it through a day's work without a hangover.

This went on for about 2 years, and by the 3d year, I had cut down my drinking and drugging, realizing my problem. But I could not quit on my own.

At the end of this year, I started getting sick from booze and pot, because I was pregnant again, this time with a child the father did not want. I knew my family would be disgusted, so I ran. I came back 1 week later, completely defeated.

I then moved into a house with a couple of people from an anonymous self-help group for alcoholics, and started attending their meetings. Three days after I had moved in, I started hemorrhaging from some heavy lifting I had done from moving. The placenta and the wall of the sac of the amniotic fluid had torn apart a little. I had been getting prenatal care, from the time I found out I was pregnant, and this time told the doctors everything truthfully.

My water broke, infection set in, and 1 week later, they had to induce labor. My daughter was born 8 weeks early. She weighed 3 pounds, 9 ounces, and is doing great in the infant IVC unit in Fairfax Hospital.

The self-help group had been a great help for me, but I needed something more. I had had a lot happen to me, and I could not share about it in meetings. So I reached out to a member in the group who I knew was also a counselor for alcohol and drug abuse. He referred me to the Women's Center for Alcoholics and Drug Abusers. That is where I found the things I needed.

I find myself opening up. As I learn more about my disease, I learn more about myself.

The key word here is education. The self-help group gave me their experiences, strength and hopes. They showed me there was life, and how to enjoy it.

The Women's Center is teaching me about my disease, and how to become more responsible, and restoring my dignity. Helping me become more independent, and teaching me not to blame myself.

They teach by one-to-one counseling, and group therapy, through films, lectures and discussions. Without them and my self-help group, I would be on my way to a very long and painful death. They taught me to forgive myself, which gives me the strength to be here and tell you my story, in hopes that I may help someone else find the kind of happiness I have now found.

My story, which is very long, and I do not have time to tell you in full, should be told to you, for you to totally understand what these people have done for me.

I lived in hell, and I am grateful that these trustworthy doors and hearts are open, and I need them.

Because of them, there is one less DWI, one less bum on the streets digging out of trash cans, one less criminal, one less suicide, and one less hopeless mother.

God bless all who have stood by me. Thank you very much.

[Prepared statement of Jennifer Custis follows:]

PREPARED STATEMENT OF JENNIFER CUSTIS

My name is Jenny Custis. I am 28 years old and am a recovering alcoholic and drug abuser.

When I was five my mother and father split up. My brother and I were left with my mother who eventually turned to prescription drugs to ease her pains. We all moved in with my grandmother and there were many conflicts and hardships. My childhood was nowhere close to being normal.

My mother died when I was 16 from emphysema and drug abuse. Between the anger I had with God for taking away my mother and the kids who teased me unmercifully for being a "Goody-Goody," I turned to tequila and marijuana to ease the hurt and so I'd fit in with the crowd.

When I was 18 I moved in with my ex-husband, who is also an alcoholic. I was 20 when I got pregnant with our first child. I quit drinking within the first month of my pregnancy because it made me sick, but I continued to smoke pot once in a while. I got prenatal care as soon as possible, but lied to my doctors about my occasional joint. My son was carried full term, weighed 7 pounds, 11 ounces, and there were no complications.

A little over a year later I gave birth to my daughter. During my pregnancy, I smoked pot and drank for the first three months. I didn't know I was pregnant. The pot and the booze started making me sick so I quit and started getting my prenatal care. I tried to get high a few times in spite of the fact it made me sick. My daughter was carried full term, weighed 6 pounds, 12 ounces, and there were no complications.

Three years and many hardships later, I got pregnant with my third child. But this time I was drinking very heavily due to stress. I drank and smoked pot the whole time I carried him, and it never made me sick. I started questioning my drinking and drugging and friends would tell me they never had anything go wrong with their pregnancies over it, so I figured it wouldn't happen to me. My son was born seven weeks prematurely. My water broke, he went into distress and the doctors took him by C-section. He weighed 3 pounds, 14 ounces. I had only been getting prenatal care a short time prior to his birth because I didn't want anyone to find out I was sick. He's doing fine now, but had some problem with muscle development.

I ended up giving up my children just a few weeks after I brought my new baby home, because we couldn't afford a roof over our heads. This gave me a chance to leave my ex-husband and left me plenty of free time to drown my sorrows. The pain I felt cannot be measured.

In spite of the alcohol and drug increase I got a job and kept it, I got a roof over my head, gained weight, eventually convinced everyone I was straight, and became more secure than I had ever been in my life. At this time, I was also doing over-the-counter speed to get me through a day's work without a hangover.

This went on for about two years. By the third year, I had cut down my drinking and drugging, realizing my problem, but couldn't quit on my own. At the end of this year, I started getting sick from booze and pot because I was pregnant again, this time with a child the father didn't want. I knew my family would be disgusted so I ran, to come back a week later completely defeated.

I then moved into a house with a couple of people from an anonymous self help group for alcoholics, and started attending their meetings.

Three days after I'd moved in I started hemorrhaging from some heavy lifting I had done. The placenta and the wall of the sac of amniotic fluid had torn apart a little. I had been getting prenatal care from the time I found out I was pregnant and this time told the doctors everything truthfully. My water broke, infection set in a week later, and they induced labor 8 weeks early. She weighed 3 pounds, 9 ounces, and is doing great in the infant IVC unit in Fairfax Hospital.

The self-help group had been a great help for me, but I needed something more. I'd had a lot happen to me I couldn't share about in meetings, so I reached out to a member of the group who I knew was also a counselor for alcohol and drug abuse. He referred me to the Women's Center for Alcoholics and Drug Abusers. That's where I found the things I needed. I find myself opening up as I learn more about my disease, I learn more about myself. They key word here is education.

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The Women's Center is teaching me about my disease, how to become more responsible, restoring my dignity, helping me become more independent and teachng me not to blame myself.

They teach on one-to-one counseling, group therapy and through films and lectures and discussions.

Without them and my self-help group, I'd be on my way to a long and painful death. They taught me to forgive myself which gives me the strength to be here and tell you my story in hopes that I may help someone else find the kind of happiness I have now.

My story, which is very long, and I didn't have time to tell in full, should be told for you to totally understand what these people have done for me. I lived in hell, and I am only grateful that these trustworthy doors and hearts were open when I needed them. Because of them, there's one less DWI, one less bum, one less criminal, one less suicide, one less hopeless mother.

God bless all who have stood by me. Thank you.

Chairman MILLER. Thank you.
Mr. Walker.

STATEMENT OF BENJAMIN WALKER, JR., CHIEF EXECUTIVE OFFICER, ODYSSEY FOUNDATION OF NEW YORK, INC., NEW YORK, NY

Mr. WALKER. Good morning. It is, indeed, an honor to join this distinguished panel and share some of the Odyssey House Parents'——

Chairman MILLER. Can you bring the microphone closer?

Mr. WALKER. OK. We are a unique, drug-free, therapeutic community of residents, for addicted parents and their children. Our specialized target population consists mainly of women who are pregnant or/and parents, but includes males and couples, who are anxious to maintain an intact family unit.

More than 15 years ago, we recognized that a specialized program was needed to break the multi-generational cycle of drug addiction and abuse. The majority of our residents are second and third generation substance abusers. We learned that this lack of family value system shows up in other areas as well.

Children who are abused grow up to become child abusers. The tremendous advantage that Odyssey House Parents' Program offers is residential psychiatric services, and skill-training to pregnant substance abusers, and drug abusing parents with young children.

This milieu of therapy includes group therapy, parenting workshops, individual counseling services for parents and children, with professional child care staff, medical staff, psychologists, child psychologists, social workers, and psychiatrists.

The Parents' Program is designed to meet the child's needs first, and the parent's second.

Living within the Parents' Program community results in the first chance that many children have had to know what it is to be loved and cared for on a daily basis. The addicted parents do not alter their lifestyle because of their child. The addicted personality does not give without expecting something in return, an impossibility for the infants. Women addicts have a destructive narcissistic bond to their children, often competitive in nature, that has to be broken before positive nurturing can begin. All of these destructive habits must be changed if their children are to break the multi-generational cycle, and have a chance to grow up as all children should.

While children adjust more rapidly to their physical surroundings, it is much harder to work through the levels of consciousness that still makes them cry in the middle of the night.

The Parents' Program provides various forms of therapy for the parents and the child to discover and work to remedy these situations.

Babies born to addicted parents often are born prematurely, have a lighter birthweight than normal. They experience periods of withdrawal, and have a far greater tendency toward illness in early infancy. They often arrive in the program sick and malnourished. There are often early developmental deficiencies, especially in attentiveness, alertness, eye movement, and reaction response.

They are often withdrawn and isolated, as they have been accustomed to being left alone for long periods of time, often crying, often without being changed. The addictied parent often blocks out the child entirely.

In the Parent's Program, the parent learns to be responsive to the child, with a positive vocal interaction and cuddling. She and the child begin to experience interaction with other children and parents. Special programs and individual treatment programs are designed, according to the age, emotional, and mental needs of the child.

These are developed and implemented by a medical and child care staff, in conjunction with staff psychologists and psychiatrists.

There are three main nurseries on the site. Infant, toddler, and preschool. Each has its own constructive environment, in which the child may grow, with the assistance and guidance of the child care staff. As with their parents, all children are given complete medical examinations within 24 hours of admission.

Some babies in the Odyssey Program were born addicted. Medical staff monitor their development and detect physical and emotional problems immediately. Often, children of drug abusers lag in various areas of age-appropriate development. We find in our 6 month to 3 year olds, much immaturity and aggressive behavior, as well as other emotional and behavioral problems.

Their individualized treatment plans are designed to enhance each child's emotional and cognitive abilities. Arts and crafts, sciences, which are basically nature walks, drama and play therapy, are some of the major activities the program provides for the children.

There is much positive reinforcement given for proper behavior, and bad behavior, or acting out behavior is never punished by physicality.

For more than 15 years, our unique Odyssey House Parents' Program has sought to break the multi-generational cycle of substance abuse, leading to child abuse and neglect. Our parents are learning to live drug-free, positive lives, and develop parenting skills and a healthy relationship with their children, who can grow up protected and nurtured, under the guidance of our child care staff. As one of our parents said, "I know my child has to feel safe before anything can go forward. It is not enough to tell her all is all right. I do not think she would believe me. Not yet. I know she remembers the bad things. I have to show her that those things are not going to happen anymore."

Ladies and gentlemen, there is light, and laughter, at the end of this tunnel. There is a chance to grow up outside the shadows of fear and abuse that abused children know too well. There is also an opportunity for an abuse-free life. As Julio Martinez, director of the New York State Division of Substance Abuse stated, "I know of nothing more important than the saving of innocent children from the tragic life of substance abuse. Odyssey House has developed a caring and compassionate program for substance abusing parents and their young children. It is truly a humanitarian and a very important service." Thank you.

[Prepared statement of Benjamin Walker, Jr. follows:]

PREPARED STATEMENT OF BENJAMIN WALKER, JR., M.P.H., CHIEF EXECUTIVE OFFICER OF ODYSSEY FOUNDATION OF NEW YORK, INC.

It is an honor to join this distinguised panel and be here today to share some of the Odyssey House Parents' Program with you. We are a unique drug-free therapeutic residential community for addicted parents and their children. Our specialized target population consists mainly of women who are pregnant and parents, but includes males and couples anxious to maintain an intact family unit.

More than 15 years ago, we recognized that a specialized program was needed to break the multi-generational cycle of addiction and abuse. The majority of our residents are second and third generation substance abusers. We learned that this lack of a family value system shows up in other areas. Children who are abused grow up to become child abusers themselves. The tremendous advantage that the Odyssey Parents' Program offers is residential psychiatric services and skills-training to the pregnant substance abuser and the drug-abusing parent with young children. This milieu of therapy includes group therapy, parenting workshops and individual counseling for the parents and children with our professional child care staff, medical staff, psychologist and child psychologist, social workers and psychiatrist. The Parents' Program is designed to meet the child's welfare first and the parent's second.

Living within the Parents' Program community is often the first chance many children have to know what it is to be loved and cared for on a daily basis. The addicted parents do not alter their lifestyle because of their child. The addicted personality does not give without expecting something in return, an impossibility for the infant. Women addicts have a destructive narcissistic bond to their children, often competitive in nature, that has to be broken before positive nurturing can begin. All of these destructive habits must change if their children are to break the multi-generational cycle and have a chance to grow up as all children should.

While children adjust more rapidly to their physical surroundings, it is a much harder thing to work through those levels of consciousness that still make them scream in the night. The Parents' Program provides various forms of therapy for the parent and child to discover and work to remedy these situations.

Babies born to addicted mothers are often born prematurely, have lighter birth weights than normal, may experience a period of withdrawal and have a far greater tendency toward illness in early infancy. They often arrive in the program sick and malnourished. There are often early developmental deficiencies especially in attentiveness, alertness, eye movement and reaction response.

They are often withdrawn and isolated as they had become accustomed to being left alone for long periods of time, often crying, often without being changed. The addicted parent often blocks out the child entirely. In the Parents' Program the parent learns to be more responsive to the child, with positive vocal interaction and cuddling. She and the child begin to experience interaction with other children and parents.

Special programs and individual treatment plans are designed according to the age, emotional and mental needs of the child. These are developed and implemented by our medical and child care staff in conjunction with the staff psychologist and psychiatrist. There are three nurseries on site: Infant, Toddler and Pre-School. Each has its own constructive environment in which the child may grow with the assistance and guidance of the child care staff. As with their parents, all children are given a complete medical examination within 24 hours of admission to the program. Some of the babies in the Odyssey nursery were born addicted. Medical staff monitors their development to detect physical and emotional problems immediately. Often children of drug abusers lag in various areas of age-appropriate development.

We find in our six-month to three year olds much immaturity and aggressive behavior as well as other emotional and behavioral problems. Their individual treatment plans are designed to enhance each child's social, emotional and cognitive abilities. Arts and crafts, science, drama and play therapy are some of the many activities the program provides for the children. There is much positive reinforcement given for proper behavior and bad behavior or acting out is never punished by physicality.

The parents awaken each day with their children and prepare them for the day, eat breakfast with their children. The children are then taken by their parents to the appropriate nursery and the parents go to their job functions in the facility. Several times each day, the parent returns to the nursery for brief periods of interaction with his or her child, observing the child at play with other children and with the nursery staff. Mothers assist the nursery staff as escort when groups of children leave the facility for day trips to parks, zoos, museums and shows. At the end of each work day (and all day on Sunday) the parents return to the nursery to spend about an hour with their own children before taking them to dinner. This hour is one of the most important of the day for parent and child, because they interact under the observation of the nursery staff and with their guidance, the parent and child begin to develop a positive relationship. This interaction continues through dinner and in preparation of the child for bed. Odyssey gradually increases the time parents spend with their children, in both supervised and casual situations. Staff meet weekly to discuss all residents and convene special conferences on particularly difficult cases. Plans for parents and children develop from a team approach.

For more than 15 years our unique Odyssey House Parents' Program has sought to break the multi-generational cycle of substance abuse leading to child abuse and neglect. Our parents are learning to live drug-free positive lives and develop parenting skills and healthy relationships with their children who can grow up protected and nurtured under the guidance of our child care staff. As one of our parents said, "I know my child has to feel safe before anything can go forward. It isn't enough to tell her things are all right. I don't think she would believe me, not yet. I know she remembers the bad things. I have to show her that those things aren't going to happen anymore."

Ladies and gentlemen, there is light and laughter at the end of this tunnel. There is a chance to grow up outside of the shadow of fear that abused children know all too well. There is also an opportunity for an abuse-free life. As Julio Martinez, Director of the New York State Division of Substance Abuse Services stated, "I know of nothing more important than the saving of innocent children from the tragic life of substance abuse. Odyssey House has developed a caring and compassionate program for substance-abusing parents and their young children. It is truly a humanitarian and very important service."

Thank you.

Chairman MILLER. Thank you.
Joyce.

STATEMENT OF JOYCE N. THOMAS, R.N., DIRECTOR, DIVISION OF CHILD PROTECTION, CHILDREN'S HOSPITAL NATIONAL MEDICAL CENTER, WASHINGTON, DC

Ms. THOMAS. Good morning and thank you.

Chairman MILLER. Please move the microphone over.

Ms. THOMAS. My name is Joyce Thomas, and I am the director of the Division of Child Protection here at Children's Hospital. I am also the chairperson of the interagency coordinating subcommittee of the Mayor's Committee on Child Abuse and Neglect.

I am pleased and honored to have this opportunity to testify before the Select Committee on Children, Youth, and Families and the topic is very, very important, and deeply of concern to myself and my staff.

Clearly, we are concerned about the problems of extensive alcohol and substance abuse in parents, and implication of such abusive behavior for our children that we see in our program. We are also concerned about the issues related to infants born of AIDS, and the issues that it poses again, for social welfare programs and the programs related to services to parents.

Let me tell you just a little bit about the division. Basically, the Division of Child Protection is a multidisciplinary treatment program, which is designed to provide care and services to children and their families, for all aspects of child maltreatment. We see large numbers of children here at Children's Hospital, a total of some 1,400 cases of child abuse, sexual abuse, each year. About 550 of those cases involve physical abuse and neglect. About 100 of those cases involve children under the year of 1 age—1 year of age.

In looking at the issues of the Mayor's committee, we are a large group of both public and private agencies, some 31 agencies, which are organized here in the city, to try to combat these problems on a larger scale. Not only in the direction of the direct care for children, but to deal with issues of policy development, problem solving, as well as coordinating services among agencies. Dealing with some of the problems of substance abuse, it is critical to have such an arena.

We are concerned about the increasing problem of parents who are substance abusers in this city. We are concerned about the risk it imposes to children who are abused and neglected. Here at Children's Hospital, as indicated earlier, we have youngsters who have severe burns, youngsters who have multiple fractures, head injuries, and many times there are situations where parents judgments are impaired by alcohol and substance abuse. Many times these children are harmed physically, as well as emotionally.

We have seen young infants and toddlers intoxicated with substances, such as PCP, and other harmful drugs. Such a problem is far reaching, and has far reaching implications, beyond even the direct physical care. They are long term social and emotional problems and developmental problems for these youngsters.

We are concerned about the issues, in terms of providing protective care. Many of these youngsters do receive, and must be placed into protective custody. We are concerned, also, about the problems of protective custody, in terms of identifying appropriate homes for these youngsters, as the numbers and the volumes of cases continue to increase.

It has long been assumed that there is a relationship between alcoholism and child abuse. However, we are really struck at the problem of poor data collection, and the inability to make such a comparison empirically. By the lack of comparison of making a connection between alcohol and child abuse, we realize we are not giving the attention deserved to this problem. There are numerous legal and ethical problems in obtaining such data. And particularly, there is a prohibition by federally funded alcohol and other substance treatment programs in identifying and working closely with child protection agencies.

I believe this is an area that we should be addressing more closely. Although it has been well documented that alcohol is a dangerous drug, we are now beginning to see real documentation of it, in fact, particularly as it relates to child abuse and neglect.

A recent factsheet, which was developed by the National Committee for the Prevention of Child Abuse and Neglect, has pointed out that there are over 28 million children of alcoholics in the United States. One-fourth of them are youngsters under the age of 18. In general, life with an alcoholic parent is characterized by fear, tension, and insecurity.

Many alcoholic treatment programs recognize the tremendous amount of emotional neglect imposed upon these youngsters. For adolescent and older children it is neglect. For younger children and infants themselves, it becomes a life-threatening situation.

We are concerned about not only the actual child that is born healthy, but the care for these youngsters in their home. We have seen a number of situations where these children have fallen, have ingested other poisons, and have been severely traumatized accidentally, while they are in a situation where the parents are unable to care for them.

According to the same factsheet, some 33 percent of all reported cases of child abuse in the State of Florida are related to substance abuse. In Massachusetts, in one courtroom alone, we realized that 42 percent of all child abuse cases involve an alcoholic mother, and 34 percent involved an alcoholic father. In the District of Columbia, almost 25 percent of 6,000 cases of child abuse and neglect reported to Child and Family Services Division of the Department of Human Services in 1985, involved alcohol abuse and emotional problems, generally related to other forms of substance abuse.

Unfortunately, it is not clear how many of these situations involve actual infants.

One major problem here in the District of Columbia, as in other cities, is the problem of PCP. PCP ingestion and other drugs, mixed with marijuana, creates an enormous problem for our youth services. Public and private youth agencies throughout the city have been struggling to deal with this problem, particularly in adolescents and young adults. And we are finding this problem has impending concerns related to children.

According to the D.C. Department of Human Services, Alcohol and Drug Abuse Services Administration, PCP was the third most frequently mentioned drug in D.C. hospital reports.

In a study that was done in 1984, we realized that at Saint Elizabeth's Hospital, 247 adults admitted for mental illness, one-third of them had confirmed positive for PCP. Another study which was done by the D.C. Superior Court, a 22-month study, we realized that some 824 youngsters who were screened, all were screened positive for PCP.

These are enormous problems, and these are tremendous amounts of problems in our social welfare system.

Anecdotally, in talking with some of the gentlemen who are looking at this problem further, they realize that PCP seems to be increasing, particularly here in the city. And there are a variety of programs which attempt to address this problem, but they still have further implications for children, and for parents with young children.

The problem is twofold here at Children's Hospital. And I am going to deviate slightly from my testimony and just tell you specifically.

We find that many parents whose child may be brought to the hospital for reasons of a physical injury, may, themselves, be intoxicated with PCP. And we realize that the injury that the child may have experienced is in direct relationship to the intoxicated status of the adult who is caretaking for the child. Such situations involve a mother who had overdosed her child with cough medicine. Another situation involved a situation where the parent was intoxicated and held a 21-day-old, premature infant upside down, until the child was breathless. And many times these children will come to us with physical findings, and many times we find we are dealing with even more major problems.

We find that many of these parents are hyperactive. They have many mental health problems. They have loss of memory. They have difficulty with judgment and have difficulty in identifying some of the needs of their children.

The problem is further increased by the situation of young children actually being intoxicated with PCP. It is unclear if these children are inhaling, or if these children accidentally get the substance. And we are aware that some of the youngsters who come to our attention are youngsters who have been newborns and have evidence of PCP intoxication.

So, we have a major problem associated with trying to treat these individuals, and trying to provide such care.

In looking further at the question, I think it would be important to realize that we saw such—10 youngsters here at Children's Hospital in the last year. We have worked with these families. Many of these children have had to be removed from their home. But many times these youngsters remain in their setting.

It is clear that we have a problem, of course, that requires a great deal of attention. And we have a problem that is associated with needing to provide better education about the problems of PCP intoxication, alcohol intoxication, as it relates to infants.

We find that these youngsters do have situations where there is decreased stimulation. There is decreased bonding. There is increased problems in the parenting relationship. There are problems associated with general health and nutrition. There is increased harm and risk for abuse. There is increased harm and risk for emotional damage for these children.

My recommendations are, I clearly want to continue our move toward education and prevention, to improve the coordination of services to these families, and to recognize, in a much more specific way, by professionals, the need to understand this problem further.

Thank you.

[Prepared statement of Joyce Thomas follows:]

PREPARED STATEMENT OF JOYCE N. THOMAS, R.N., P.N.P., M.P.H., DIRECTOR, DIVISION OF CHILD PROTECTION, CHILDREN'S HOSPITAL NATIONAL MEDICAL CENTER, WASHINGTON, DC

Good morning. My name is Joyce N. Thomas and I am the Director of the Division of Child Protection of Children's Hospital National Medical Center here in Washington, DC. I also serve as the Chairperson of the Interagency Coordination Subcommittee of the Mayor's Advisory Committee on Child Abuse and Neglect. I am pleased and honored to have this opportunity to testify before the Select Committee on Children, Youth and Families on a topic that has deeply concerned me for some time--abuse and neglect of young children by parents who indulge extensively in alcohol and/or illegal drugs such as cocaine and PCP. In addition, I am concerned about the problems of infants born with positive HTLV3 antibodies (AIDS). If these children need foster care they are hard to place, and the societal stigma may remain with them for life.

To begin, let me provide some brief background information that shapes our Division's orientation. We are a specialized program concerned with all aspects of child maltreatment; we are a multi-faceted unit, using a combination of approaches at every level of intervention, from direct services through special projects to community advocacy for abused and neglected children and their families. Last year we served more than 1,400 new cases of physical abuse, neglect, and sexual victimization that presented to the hospital. We provide medical care, mental health services, social services, case management coordination, professional training, public awareness, parent education, child advocacy and prevention programs to children, parents, professionals, and community groups.

The Mayor's Committee is composed of 31 public and private agencies, organizations, and community advocacy individuals who meet to advise the Mayor, provide coordination of the many agencies involved in the complex medical, legal, mental health and social welfare systems involved, and provide community education.

The increasing problem of parents who abuse substances is a major concern to the Division and the Mayor's Committee. Parental addiction and chronic intoxication are placing more and more infants and young children at risk for abuse and neglect.

Here at Children's Hospital we have seen many infants with severe burns, multiple fractures, and head trauma from parents whose judgment is impaired by extensive alcohol consumption and/or addiction to heroin, cocaine, and PCP. We have also seen infants who are intoxicated from ingesting these substances. Such a problem has far-reaching implications for both the short-term physical health and the long-term social, emotional, and developmental growth of infants who live in environments where substance abuse is a parental problem. Many of these children must be taken into protective custody and the states' child welfare systems are overwhelmed in attempting to find homes for children with special needs.

It has long been assumed that there is a relationship between alcoholism and child abuse and neglect. However, the issue has been poorly researched and there is comparatively little empirical data. There are legal and ethical problems in obtaining such data; in particular, the prohibition for federally funded alcohol and other substance abuse treatment programs from disclosing information to outside agencies, including child protection agencies, has been a major hindrance.

Although it has been well documented that alcohol is a dangerous drug, we are just beginning to demonstrate the relationship to child abuse and neglect. A recent fact sheet developed by the National Committee for the Prevention of Child Abuse has pointed out that there are more than 28 million children of alcoholic parents in the U.S.; one fourth of them are under the age of 18. In general, life with an alcoholic parent is characterized by fear, tension, and insecurity. Many alcoholism treatment programs identify emotional neglect as a major theme for the children. For infants, the neglect can literally be life-threatening as parents under the influence fail to prevent falls from outside balconies, burns, ingestions of poisons, etc. We have also seen children with severe trauma who were accidentally hit or dropped in the middle of an altercation between their intoxicated parents.

According to the fact sheet, 33% of all reported child abuse cases in Florida are related to substance abuse. In Massachusetts, in one courtroom alone 42% of the child abuse cases involved an alcoholic mother and 34% involved an alcoholic father. In the District of Columbia, almost 25% of the 6,000 cases of abuse and neglect reported to the Child and Family Services Division of the D.C. Department of Human Services in 1985 involved alcohol abuse and emotional problems. Unfortunately, the number of these children who were infants is not reported.

Our second major problem here in the District of Columbia, as in other cities, is phencyclidine--PCP--also known as "angel dust", "love boat", "lovely", and "clicker," when mixed with a marijuana cigarette. Public and private youth-serving agencies throughout the city are struggling to deal with adolescents and young adults--the age group most likely to have young children--who use PCP.

According to the D.C. D.H.S. Alcohol and Drug Abuse Services Administration, PCP was the third most frequently mentioned drug in District hospital reports, surpassed only by alcohol and heroin. In a four month period in 1984, St. Elizabeth's Hospital admitted 247 adults for mental illness; one third of these have been confirmed as related to PCP use. During a 22-month study by the D.C. Superior Court's Family Division on juvenile delinquents under court mandate, 82% of those screened were positive for PCP.

PCP use is also related to preschool aged children. Although intoxication and addiction in newborns and young children have been reported only sporadically in the professional literature, such reports have been increasing.

In the past several months our Division staff has seen an increased number of cases in which PCP use is related to abuse or neglect. These cases have included a mother who attempted suicide and mutilation of her infant; a PCP-intoxicated mother who gave her 2-month-old infant an overdose of cough medication; PCP-using parents who dropped a television on their 2-week-old infant during a fight; and a 21-day-old premature infant who stopped breathing after her intoxicated father held her upside down.

In our observation of these parents, we have noted that some reveal various levels of disorientation, euphoric affect, hyperactivity, grandiose and paranoid delusions, loss of memory, and grossly impaired insight and judgement. Such symptoms are never clear but are related to several other complex factors in the parents' lifestyles that contribute to their unusual behavior in the Emergency Room.

In addition to the problem of PCP-intoxicated parents, we have seen about ten children during the course of a year ranging in age from newborns to pre-school who have ingested or inhaled the drug. (These cases involved six males and four females; six were from D.C. the others from Maryland and Virginia.) The most distinctive finding was a dull, trance-like facial expression; other notable symptoms were agitation alternating with lethargy, increased salivation, seizures, minimal reaction to pain, apnea, ataxia, and other central nervous system changes. Several were nonresponsive at their arrival in the ER. Their ingestion or inhalation was confirmed by a specially requested PCP drug screening. Their stay in the hospital was generally brief, however, several of the children had to be taken into custody for their protection and three had to be admitted to the ICU. The possible causes of their intoxication include fetal transport, ingestion, and possible inhalation from someone smoking PCP in the child's presence. While it is difficult to generalize from a small number of cases, the potential grave consequences make it imperative for us to recognize this problem.

There are a number of forensic questions that require further study with respect to children's intoxication from PCP. One major problem is the level of urinary PCP does not necessarily predict the severity or range of symptoms. A second problem is that information gathering from the parents is usually limited; parental denial or ignorance of PCP makes information about the amount, route, timing, and frequency of the drug's use unreliable. Since PCP crosses the placenta and may harm the fetus, and since it has been found in the breast milk and amniotic fluid of mothers, many infants are potentially at risk. We do not yet know whether such infants will show the long-term symptoms and behavioral changes of adolescent and adult users of the drug; if so, our child welfare and mental health systems will have an overwhelming problem in the years to come in providing necessary services. For those children who are not taken into foster care monitoring and follow-up are problematic.

Infants at risk for AIDS because of their parents' illness or their own early symptomatology are difficult to place in the foster care system. We are confronted with such problems here at Children's Hospital. The difficulties in terminating the parental rights of AIDS children in foster care and in finding adoptive homes for them may create a new class of children for whom the permanency planning goals of the Adoption Assistance Act of 1980 remain elusive.

Special needs children who are abused and neglected by their parents often linger in public custody, moving through a series of foster and group homes and institutions without families or homes to call their own. A major social question facing us is how we can better meet the needs of these children and their families.

Looking to the future, it appears that we have much to consider as we ponder the problems of infants at risk due to parental addiction and disease. Obviously, well coordinated critical medical care and child protection services are essential elements in our fight to perserve the life of these infants. We need to do much more in the areas of prevention and public education about the problem.

As a society, when we hear of the problems of drugs and alcohol we often feel it is someone else's problem. We still tend to merely focus on and blame the individual drug abuser. It's hard not to fall into that posture. We seldom focus on the problems of these vunerable infants, on the images of fractured, burned and battered infants. It is not surprising that we seldom know what to do when we are presented with the problem of infants at risk due to parental substance abuse or disease.

In closing, parental substance misuse, especially when it is of the psychoactive drugs (alcohol, barbiturates, narcotics, and hallucinogens) translates into an abundance of physical, emotional and social problems for infants and children. Each of these problems becomes in turn a different stressor to the family, amplifying the problems of unemployment, poor housing, immaturity, and generalized family disfunctioning that have frequently contributed to the parents' use of drugs, alcohol, and to their vulnerability to diseases like AIDS. Thus, both the parents' and children's problems may become worse, leading to new generations of misery. Clearly we must break this cycle, using our best research, education, and services to reduce parental substance abuse and help their children. Such an effort will not be inexpensive, but the fiscal and social costs of failing to attempt this effort will be even greater.

My recommendations include the following:

1. We need continuous major public education on the problems of drugs and alcohol abuse with specific focus on the tremendous harms and potentially life-threatening problems of infants and young children. Mass public service announcements and public media efforts are needed.

2. We need to collect more data to document the extent of the problem. Such information is needed to improve professional awareness of the problems.

3.Specialized treatment programs for pregnant women and adolescents should be established. Such rehabilitation programs must include counseling services, job training, self-help groups, in-home services and detoxification capabilities.

Finally, the problems of substance abuse are intricate and pervasive throughout our society. Whether these problems occur in multiproblem environments or in middle class environments, services must be provided for infants born in these homes.

CHILDREN'S HOSPITAL NATIONAL MEDICAL CENTER

DIVISION OF CHILD PROTECTION
PCP PROTOCOL

STATEMENT OF POLICY: All cases of PCP (Phencyclidine) intoxication in children six (6) years old and younger who present in the CHNMC emergency room or other hospital units will be referred to the Division of Child Protection.

RATIONALE: The confirmed diagnosis of PCP ingestion or inhalation in children six years old and younger may be an indication of neglect if not abuse, and has grave implications for present and future medical, legal, and psychosocial intervention. Child protection and advocacy, as well as the development of a research and education oriented information gathering system, are the ultimate goals of DCP intervention.

IMPLEMENTATION:

I. Diagnosis

A. PCP intoxication should be considered when a child presents with:

1. mental status changes of unknown etiology
2. neurological and autonomic disturbances
3. abrupt and disturbing changes in behavior
4. allegation or admission by the parent(s), caretaker, or other informant of exposure to PCP.

Other conditions such as seizure disorders, infectious processes (meningitis), head trauma, metabolic derangements, brain tumors, and other types of drug ingestion must also be considered and ruled out as the diagnostic process continues.

B. Diagnosis of PCP intoxication is made through use of the toxicology services of the CHNMC Department of Laboratory Medicine. Drug screening for children suspected of having ingested PCP will be handled in two major ways:

1. If the child presents with symptoms suspicious of drug intoxication and the person accompanying the child states that PCP was present in the child's environment, a qualitative screening test for PCP can be ordered. For this test, 10 ml of urine and the appropriate toxicology request form are required,and the results will be available in approximately one hour. If the PCP screening is positive, the laboratory will automatically confirm the presence of PCP in urine by gas chromatograph-mass spectrometry. This confirmation, however, will not be available on a STAT basis.
2. Most often the child will present with symptoms of drug intoxication, but knowledge of ingestion of a specific substance will be unknown or denied by accompanying adults. In this case 20 ml of urine with a requisition for a comprehensive drug screen will be sent to the lab. This test will take approximately three hours.

3. The physician requesting the lab work must consult with the Chemistry Director on call (5339 or hospital operator) regarding the need for the emergency toxicology screening. The Chemistry Director will require information about the clinical state of the patient, the details of the emergency, and the nature of the physician's treatment decision with or without the drug screening results. Treatment may need to proceed before lab results are known.
4. If the physician suspects that there may be an element of child abuse or neglect involved in the ingestion or inhalation, he/she must initiate documentation by filling out a medico-legal chain of possession form available for this purpose (see attached sample). Often the lack of a clearly completed medico-legal chain of possession document is what results in the rejection of evidence in court.
5. No quantitative test (drug level) can be ordered on a "stat" basis; furthermore there is a poor correlation between the level of PCP and the presence or severity of symptoms.

C. When the diagnosis of PCP intoxication is confirmed, the on-call DCP clinician must be contacted immediately. The family should be told of the imminent DCP involvement and asked to remain until the arrival of the clinician. Upon arrival the DCP clinician needs to:

1. Consult with medical and nursing staff in order to obtain factual information, and complete the attached symptom checklist.
2. Introduce self to family members and explain the role of the DCP.
3. Obtain a complete history of events surrounding the PCP ingestion or inhalation from the family members or child him/herself, if possible.
4. Notify the DC MPD Youth Division, DHS Child and Family Services, and officials in other localities, when indicated, of the positive PCP intoxication. The DCP director, physician, and back-up consultant should also be notified. The DCP clinician should decide with the responding Youth Division officer whether a report to the DC MPD Narcotics Squad is appropriate.
5. Coordinate the details of medical, legal and psychosocial involvement.
6. Formulate a plan for follow up.
7. Offer support and counseling to the child and family.
8. Complete DCP intake forms and obtain appropriate signatures on legal release of information forms.

D. Treatment

The following care and treatments may be indicated depending on the presence and severity of symptoms:

1. Observation of the child in the ER or other hospital units. This should include the monitoring of vital signs and documentation of other symptoms and behaviors.
2. A controlled environment may be necessary to prevent physical and/or psychological harm to the child. This may require safe physical space as well as one-on-one care by a staff member.

3. Treatment of individual symptoms or medical conditions caused by the drug:
    a. Gastric lavage, or hydration to more speedily rid the body of the toxin. Acidification of the urine may be useful.
    b. Respiratory support if this vital function is compromised as a result of the ingestion.
    c. Medication to control symptoms (e.g., Haldol or Narcan)
    d. Psychiatric consultation if specialized intervention is required to manage symptoms.
4. Hospitalization for further observation and treatment, if warranted by the medical or psychological condition.
5. Removal of the child from the home into temporary shelter placement depending on the resolution of safety and protection issues. The Youth Division officer has the authority to make this decision.

E. Follow-up
1. A medical appointment for the child shall be made for one week after the incident of positive PCP intoxication as a part of the monitoring component of care. As this time the child will be examined for any remaining or further indicators of drug intoxication. Additional lab tests may be indicated at this time.
2. An appointment with the DCP clinician shall also be arranged for purposes of case coordination and further psychological assessment and counseling.

Demographic Characteristics and Information Checklist:

Child:
- Name
- Address
- DOB
- Sex
- Race
- Measure of Developmental Level *
- Perinatal history
- School and Grade
- Source of Primary Medical Care
- Siblings (names, dates of birth)

Parent-Caretaker(s):
- Name
- Address (attempt to verify by checking an I.D. such as a driver's license)
- DOB
- Family & Household structure
- Caretaking arrangements
- History of substance abuse
- Psychosocial problems

Situational Characteristics:
- Indicate probable date, time, place, and mode of PCP ingestion or inhalation: the who, what, when, why, where, how
- Indicate denial of any knowledge of the presence or ingestion of PCP by parent(s), other caretaker, or child.

Symptoms Checklist

Violence ______
Bizarre behavior (describe) ______
Agitation/Irritability ______
Drowziness/Sedation ______
Lethargy/Stupor ______
Hallucinations ______
Fixed stare /Staring spells ______
Posturing/Opisthotonus ______
Slurring of speech ______
Ataxia ______
Intermittent periods of unresponsiveness ______
Coma ______
Poor feeding ______
Miosis ______
Hypertension ______
Hypotension ______
Seizures ______
Respiratory distress/Apnea ______
Tachypnea ______
Tachycardia/Arrythmias ______
Dystonias (rigidity or jerking movements) ______
Others ______

Laboratory Findings

____ Presence of PCP in urine
____ Results of other diagnostic tests
____ Presence of PCP in urine on follow-up visits

____
Joyce N. Thomas, RN, MPH
Director DCP

____
Mike Altieri, M.D.
Associate Director
Emergency Room

____
Roger Boeckx, Ph.D.
Director, Clinical Chemistry

/bcb
CPPCPProtc

- What percentage of sexual offenders are adolescents?
- Who is legally required to report suspected cases of child physical abuse, neglect, or sexual assault?
- The best ways to detect the presence of semen on tissue and clothing?
- The most effective methods to stop parents from re-abusing their children?

These questions only skim the surface of the complex and often controversial field of child protection. Your professional decisions in these cases can have a dramatic effect on a child's safety and a family's integrity.

Child abuse is a major national problem. Studies indicate that a child is physically abused or sexually victimized at least once every two minutes. Improving the skills and expertise of professionals involved in the management of child maltreatment cases is vital if children are to receive appropriate, sensitive treatment.

The Division of Child Protection of Children's Hospital in Washington, D.C., provides education and training programs for people involved or concerned with all aspects of child welfare. This includes programs for professionals within the medical, health care, legal, law enforcement, social services, education, and mental health fields. All training programs are individually designed to meet the needs of the particular audience and can be general or specific in scope.

Training programs provided by the Division encompass these and other issues:

Physical Abuse and Neglect –

- ***Medical*** – The battered child syndrome; new imaging techniques used in diagnosis of abuse; comprehensive assessment of physical trauma; non-organic failure-to-thrive as an indicator of neglect.
- ***Legal*** – Criminal and family court procedures in abuse and neglect cases; malpractice issues; legislative innovations in child protection law.
- ***Mental Health and Case Management*** – Behavioral indicators of abuse and neglect; social and emotional dynamics that cause parents to abuse children; parenting education as an abuse prevention technique.

Sexual Abuse –

- ***Medical*** – Medical indicators of sexual assault; forensic evaluation of child victims; diagnosis and management of sexually transmitted diseases in prepubertal children;
- ***Legal*** – Criminal and family court procedures in sex abuse cases; confidentiality and informed consent; how to prepare a child for court testimony; corroboration of evidence.
- ***Mental Health and Case Management*** – Crisis intervention techniques; how to interview a child victim; assessment and and treatment of adolescent sexual offenders.

The Division of Child Protection is a special unit of Children's Hospital National Medical Center in Washington, D.C., which provides comprehensive services to physically abused, neglected, and sexually victimized children and their families. Through clinical services, child advocacy programs, and public and professional education, the Division has pioneered several innovative programs in child maltreatment case management.

Training activities are an integral part of the Division's mission. The Division conducts almost 100 training sessions each year, addressing the concerns of professionals in the field.

Established in 1978, the Division is a national leader in the field of child protection. The Division was named an Exemplary Program by the National Institute of Justice, U.S. Department of Justice, and a Model Program by the National Organization for Victim Assistance. Since 1979, the Division has sponsored the biennial National Conference on the Sexual Victimization of Children.

Training programs are conducted by the professional staff of the Division of Child Protection. Faculty includes social workers, psychologists, clinical nurse specialists, a pediatrician, and a lawyer. All have academic preparation at the graduate level and extensive clinical experience. Division staff have published numerous professional articles and participate regularly in regional and national conferences on child maltreatment.

Training programs are available for professional and lay audiences and include speeches, presentations, and workshops. Training fees depend on the type and length of the training requested. The Division recognizes the fiscal restraints of many organizations and offers some services on a sliding scale.

Education and Training Coordinator
Division of Child Protection

Children's Hospital
National Medical Center
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Chairman **Miller**. Thank you very much.

Dr. Chasnoff, are you saying that 25 percent of the population has abused cocaine at one time or another?

Dr. **Chasnoff**. No.

Chairman **Miller**. No?

Dr. **Chasnoff**. The most current figures did come out from the National Institute on Drug Abuse show that 25 percent of the population is using cocaine at some point. The figures for pregnant women are not clear, though, because there is no national registry to keep a central record of pregnancies complicated by cocaine use.

Chairman **Miller**. Well, let us assume that if 25 percent of the population is using cocaine at some time or another, it is cutting a pretty wide path across socioeconomic lines——

Dr. **Chasnoff**. That is right.

Chairman **Miller**. I just wondered if you can describe how that use is reflected in the population of pregnant women, in terms of people from all income levels, from all different kinds of neighborhoods, in terms of your studies at Northwestern. Maybe Dr. Oleske has looked at PCP use, also.

Dr. **Chasnoff**. When our program first started in 1976, we were mainly working with women who were heroin addicts, the great majority of whom were coming from the lower socioeconomic classes, in the ghettos of the Chicago area.

As our program progressed and the word got out on the street, however, that we were available for good medical care, as well as nonjudgmental intervention, we started seeing our population change, in that the women who were coming into our program were younger, and they were coming more from middle-class backgrounds.

In the last 2 to 3 years, as cocaine has taken hold of the Chicago area, we now have—we now serve a broad spectrum of the population. We have women from the North Shore, Winnetka, Wilmette, Kenilworth, where cocaine is served at afternoon teas. We have high school girls who have become pregnant. We have college women who have become pregnant while using cocaine, at a sorority party. And it is still in the lower class, also.

Cocaine in the Chicago area, currently, is less expensive than marijuana, so that it is crossing all socioeconomic lines, and it is crossing all age groups. There is no distinction between any one group or another, as far as drug use and drug involvement is concerned.

Chairman **Miller**. Mrs. Finsterbusch, your women's center is located in Fairfax or Falls Church?

Ms. **Finsterbusch**. It is located in Vienna, VA.

Chairman **Miller**. In Vienna. So you serve that entire area, is that correct?

Ms. **Finsterbusch**. We serve all of Fairfax County.

Chairman **Miller**. So, again, the women that are coming to you or are referred to you, are a cross-section of the American society?

Ms. **Finsterbusch**. It is a complete cross-section, covering the entire range of socioeconomic levels.

Chairman **Miller**. What is the biggest problem, in terms of getting women to come to you at an early enough stage? Listening to Jenny, it is clear she went through a period of years without any help, without any support. How do you get women to come in earlier? What are the barriers?

Ms. **Finsterbusch**. Well, as—one of the—I would say the major challenge for the women's center is to try to unlock some of these historic barriers to treatment for women, the primary one being the stigma attached to the disease of chemical dependency—alcoholism and drug dependence.

That, of course, feeds the psychological component of the disease, which is denial. Between the stigma and denial, I would say that is by far the most difficult barrier to overcome. And the women's center is trying on a number of different fronts to reduce that stigma and to reduce the denial.

Early identification and timely initiation of treatment are certainly, very important—one of the very important points in our public mandate.

Public education is one of the methods—the primary method for early identification. And reduction of stigma, again through education, but also through the whole way that we are trying to be in the community—projecting a dignified, respectable public image.

Chairman **Miller**. Jenny would be typical. You rely on trauma to drive them into the program? I mean, they go through a cycle of experiences?

Ms. **Finsterbusch**. I would say that Jenny is not typical. Jenny has sought help on her own initiative. She was not compelled into treatment through the criminal justice system, or through any external force. It was simply her own very extraordinary ability to acknowledge a problem within herself, and to want to do something about it. That, in itself, is something very unusual.

She also sought help at a relatively early stage in the development of her disease.

While it is true that she suffered a great deal before she got help, she is still a young woman, and it is still relatively early in the progress of her disease compared to what we usually see in women entering treatment.

Women usually enter treatment at a much later stage of their disease, far more debilitated physically and psychologically, and under some type of compulsion. So, Jenny is not a typical case.

Chairman **Miller**. And you relate a good portion to their coming for help later in the development of the problem because of the stigma?

Ms. **Finsterbusch**. Yes. Even the family and loved ones of an alcoholic or drug dependent woman will typically deny that there is a problem, will cover up the problem, instead of encouraging her to seek help.

Chairman **Miller**. Dr. Chasnoff you mentioned you see women from the North Shore or other neighborhoods. How do they come to you? Is it pregnancy that is the event that——

Dr. **Chasnoff**. Pregnancy is usually the initiating event.

I should add to what was just said that one of the problems in identifying drug abusing women early is the poor record of the medical community in identifying these women. Physicians have not, in the past, been trained to deal with substance abuse. Many of them will ask, in a very offhand way, you do not use drugs, do you? And then turn away. And many of the women, if they had the chance, would talk to their physicians. We do get some physician referrals into our program. But these are in the minority. Most women come to our program through self-referral.

They have heard about our program, they begin experiencing some complications with their pregnancy. Then they will come in.

Chairman **Miller**. So, again, you are suggesting they come to you at a late stage?

Dr. **Chasnoff**. Well, some of them do come to us in the first part of their pregnancy. But many of them come in the last part of pregnancy, when they finally start getting scared about what they have done to their baby.

Chairman **Miller**. In your testimony, you mentioned a program at Northwestern Memorial Hospital that has provided for a reduction in the average period of hospitalization for these infants. And I am not quite clear from the written testimony how that was achieved.

Dr. **Chasnoff**. Well, the program—what was happening, it was really self-defense, in that the hospital was spending an inordinate amount of money and staff time on infants whose mothers were pregnant and were active drug users, were receiving no prenatal care, or showing up at the hospital and delivering these infants, and deliberately leaving to go back to their drug using life. And we were left saddled with infants who suffered all the complications of prenatal drug addiction, in that they were born prematurely, there was a high rate of death. Many of them who lived stayed in the intensive care nursery for, usually, at least 6 weeks.

So, the hospital knew that it had to do something. Our approach, from the beginning, was that these women needed more than medical care. And so three departments within the hospital came together—the departments of psychiatry, obstetrics, and pediatrics—to develop a multifaceted program. So that now women are, through advertising and through trying to get the women in various public service messages, that women know that we are there. We encourage women to come before they are pregnant. But many of them come by—at least—as soon as they find out they are pregnant.

And they enter into our program, where they receive intensive obstetric care, as well as individual psychotherapy, group therapy, family therapy, special Lamaze classes. We encourage, if there is—if the father of the child is not in the picture, we encourage them to come in with a significant other, to participate in some of the educational classes. And we teach the women—our goal is to get them off of drugs. And at the same time, we teach them how to handle the infants.

Chairman **Miller**. The reduction that you achieved was by getting to those women——

Mr. **Chasnoff**. By prenatal care.

Chairman **Miller**. Prior to pregnancy, or very early in the pregnancy, and starting to work——

Dr. **Chasnoff**. The single biggest factor in the morbidity and mortality of these infants is the lack of prenatal care of the women. The lack of care during pregnancy. So that by—there have been many studies that have shown that by simply getting women into an environment in which they can be encouraged to—many of them continue to use drugs, but at least get some intervention early in pregnancy, so that there is some medical care for their complications, you can lower the incidence of neonatal, or infant illness and death.

And that was our—our primary goal was to get these women into prenatal care. And second, to keep women and children together after birth.

Chairman **Miller**. Do you—do you have a figure? What does it cost the women for of those 9 or 10 months?

Dr. **Chasnoff**. We are currently funded for about $200,000 a year, which is approximately half the cost of our program. And we carry about—we currently have about 50 to 60 women enrolled in the program in various stages, prepartum and postpartum. If I had a calculator I could tell you that you achieve a great financial gain with a large amount of money saved, by providing the prenatal care.

For instance, if you find the woman has syphillis during pregnancy, it is a simple shot of penicillin, which costs about $10, plus any lab test that you need to take, to do, to make sure that she clears up and all.

If that woman were not treated for syphillis, you then have a child born with syphillis, who is going to require intensive medical care for many, many years.

Another example is a woman who is an active heroin user. If you get her into a program where you can provide psychotherapy, as well as methadone maintenance, which is the current—currently the choice, medically, to maintain these women on methadone, and get them off of street drugs. You have a child who goes through some very mild withdrawal, and usually is home within 3 to 4 days, and we can follow that infant as an outpatient.

If that child is—if the mother continues to use heroin during the pregnancy, that child is born with major complications, including severe withdrawal, a high incidence of infection, a high incidence of prematurity. So then, you are getting back into the whole long cycle of 6 to 8——

Chairman **Miller**. Are you talking less than a couple of thousand dollars a pregnancy?

Dr. **Chasnoff**. Oh, certainly.

Chairman **Miller**. We heard from the Institute of Medicine that they thought if you could get to women prior to pregnancy, or at the time of knowledge of the pregnancy, that you could provide this kind of program for somewhere for between, I think, $600 and $800.

Dr. **Chasnoff**. Certainly.

Chairman **Miller**. And the choice—the other choice is, obviously, what we saw upstairs, which, as you say, is roughly $1,000 a day.

Dr. **Chasnoff**. If you are looking at the immediate effects, also. The long term effects—the older children in our program that we have found, we have 7- and 8-year-old children, now, whose mothers were heroin users or PCP, or any of the other drugs that you have heard about today. These children, once they get into school age, are many of the children who are at very high risk for learning problems and psychological problems.

For an example, in our program, we have realized, as we did developmental testing on infants, that by about 2 years of age, the infants were beginning to fall off in their language abilities. But these infants, once they got into programs with other children, were having difficulties communicating with other children, as well as with teachers. And they were being labeled by the school district, immediately that they were learning disabled.

So we started a very simple program. First, by a year of age, we had all the women enrolled in our program take reading lessons. We taught them how to read. Because many of the women could not read. If they could read, or once they learned to read, we then taught them how to read a story to a child.

Now, this may seem like a very simple thing. You put the child on your lap, you put the book here, and help focus the child on words and on action and on turning pages. These are very simple things that you can do, but we were able to raise the language scores of our infants by a marked level. So that these infants, by 3 and 4 years of age, their language abilities, because of a simple fact of teaching mothers how to communicate.

A simple—one of the things we have done, also, is brought volunteers into our program. I have a small private practice also, that I can pick up good mothers from my private pediatric practice, and they come in and serve as role models. Many women who come from an addictive background have very poor models as mothers. So that they do not know how to be mothers. And a simple—one thing I saw at our program was that one of the mothers from my—one of the good mothers from my practice came in, and she began talking to her child, and she got down on her knees, to get on the same level as the child, and talk, face to face, with that child.

Now, we know in child development this is a basic fact, that you must provide eye contact for children. Many of these women did not know it. But they noticed this mother doing that. And now we have all our women down, crouching down to talk to their children.

So, you are not talking up here and the child is down here, but you are coming face to face. This makes a marked difference in that child's ability to learn, to express himself, and to have a feeling of acceptance, that someone was speaking directly with him.

These are very simple things that can be done.

Chairman **Miller**. Thank you. Mr. Coats.

Mr. **Coats**. If one thing has come through loud and clear this morning, I think it is that the problems and costs are so excessive, in cases like AIDS and so forth. The prospects of success are so limited that we ought to be focusing as much of our effort on prevention as we possibly can.

May I ask the panelists here to look at the prevention side, what would you recommend? What are the one or two most important things we could do to prevent the problem from happening in the first place.

Maybe I will just start on this end. I want to come back to you, Jenny, with another question.

Mr. **Walker**. I would focus on the very—we are in the situation where we are—in New York, are experiencing a crack epidemic. And we are hearing stories where 6 and 7 year olds are being introduced to crack. It is very difficult for a pusher to show a needle to a child and say, let me inject you with heroin, because it is very scary. The colorful drugs might be interpreted as candy. Kids might be reluctant to take that.

But having cigarettes, and insulated with crack, and say, take a puff of this. Most of the children will be willing to take a puff off the cigarette, because they see their role models and everybody smoking. And so, we are finding the new phenomena, where the 6 and 7 year olds are becoming addicted to crack. And prevention has traditionally focused on second and third graders and so forth. I see a need for preschool orientation, in terms of prevention services.

And informing the parents. And letting the parents know—the family—what is going on in the streets and how their kids are—you know, crack is available by school lunch money at this point. You can buy crack for $1, $1.50. That is how cheap it is.

The teenagers are—who traditionally sold marijuana are selling crack now, because there is such a huge market in New York.

So that is the main focus I would focus on is the younger generation.

Ms. **THOMAS.** I would approach the problem of prevention on a number of levels. First of all, we still have large numbers of parents who really do not understand the issues of parenting.

And we are fortunate here, at Children's Hospital, to have a program called PACE, where we actually work with parents who have abused their children, with the goal of helping to rehabilitate these families, so that these children will know a more positive relationship.

Clearly, we have to work directly with the children at the same time you are working with the parent. And covering a variety of topics, both educational topics, as well as social skills building for the children.

But the larger scale, really, is the societal question of prevention. Of understanding, really, that we are talking about a major problem in this country. We are talking about people's attitude toward children. We are also realizing that people have still very negative and misperception—misinformation about alcohol and substance abuse in adults. Usually, there is a lot of blame placed on these individuals, when there is not a lot of support systems of the kind.

I generally like to recommend people being friendly to a family with children. It is very stressful being a parent, and many times it is difficult to have that support person. But that is a very basic and simple request. But many times people are left without the supports of day care and the supports of just being able to get away from it all.

For many of these factors—there is no one simple answer. It is essential for us to use a variety of approaches. The prevention really needs to be both primary, secondary, and tertiary, to break the cycle. With the children, with the parents, and with society as a whole.

Chairman **MILLER.** Doctor?

Dr. **CHASNOFF.** I think Ms. Thomas addressed the social issues. I think I will go back to the specific issue I mentioned very briefly earlier, and that is the role of physicians.

When a woman comes in for prenatal care, she routinely has a urine sample collected to screen for diabetes, to screen for protein in the urine, to screen for infections. But toxicology—that is testing the urine for drugs—is not done by physicians.

We instituted a program in our hospital that every woman who came—and this was several years ago—1981—every woman who came to the hospital for 2 months, we tested their urine. It was a blind testing, so we did not know whose urine we were testing, so we did not get into problems of confidentiality. But we wanted to see what the incidence was.

At that time, over just a very short period, we found that 3 percent of all women coming in to deliver had, in the previous 24 hours, used some drug, such as valium, marijuana, PCP. And this went across a broad range of women, from all social classes. I can guarantee you if we conducted that study again, the percentage would be much higher, because of the recent advent of cocaine.

I think physicians must become comfortable with addressing the issue of substance abuse, both in young children, adolescents, and also in adults—especially pregnant women. And if a woman's urine does turn out to be positive, then we must take the responsibility to help her get help. This is probably the single most important factor, from a medical viewpoint, is to identify the population at risk, and then work with that poulation.

Ms. **Finsterbusch**. I would like to agree with what Dr. Chasnoff said about the importance of the role of the medical community. To have the support of the medical community would be a tremendous bonus for those of us who work in the field of alcoholism and substance abuse treatment.

Generally, that support is not there to the degree that we feel we need it. But specifically, I would like to put in a plug for there being more programs, such as the Women's Center Program, which has just opened, by the way. Our official opening was last Friday. It is a grant-funded project, with Federal set-aside money, through a block grant to the State of Virginia.

Specifically, to provide treatment services for women. To address the special, specific needs of women in treatment. And I am not talking about pregnant women, exclusively, but any woman who suffers from a problem of alcoholism or drug dependence.

Special, separate services for women are very unusual in this country. And the only programs that I know of that exist of that sort, the type that we have, have been initiated and funded by the Federal Government, either directly or indirectly through cooperation and sharing with the States and counties.

I said a few minutes earlier that Jenny was unusual in the sense that she sought help voluntarily, through her own initiative. In the very short while that we have been open at the Women's Center, we are starting to see a lot of self-referrals. Just yesterday, we had three women call on their own initiative, asking about coming in for an appointment, to see about getting some treatment for themselves. They were under no compulsion of any kind.

I think the reason is because we are providing special services for women. In the majority of treatment programs, less than 20 percent of the patient population is female. That means that a woman going into treatment, she might be—there might be one woman to five men.

It is not unusual in a 20-bed unit—not unusual for there to be only one or two women in treatment at any given time.

Mr. **Coats**. If I could interrupt you, I think it is important what you are doing. That treatment helps prevent worse problems down the line. But how do we get to the prevention aspect, so that there is not a need for your place?

Ms. **Finsterbusch**. OK, when I am talking about prevention, I am interpreting that word in terms of prevention of problems for children born to substance abusers.

Mr. **Coats**. I understand that.

Ms. **Finsterbusch**. Prevention of those problems——

Mr. **Coats**. But we are lessening the problem through your efforts, which is important, and which we have to do. But how do we address the problem in the first place? I know there is not a simple answer. That is why I am asking the question. I was just wondering if you had given it any thought, and had any perspective.

Ms. **Finsterbusch**. Well, what I am saying is—and maybe this is not a complete answer to your question. But what I am saying is that if a woman is abstaining completely, and is in recovery—if her problem is in remission at the time that she becomes pregnant, and remains in remission for the rest of her life, we should not see any problems, then, with the children, of the type that we have been talking about today.

Mr. **Coats**. OK. Dr. Oleske.

Dr. **Oleske**. Well, I think I have to disagree with that last statement, only because of our experience in Newark, NJ.

In some ways, the previous speakers all have it good. The introduction of AIDS infection in IV-drug-abusing mothers, changes all of this. If you thought you had troubles now providing services, wait until you see your population develop AIDS, like they have in Newark, NJ.

Right now, 70 percent of our drug-using women in New Jersey, all in urban poverty areas, are positive for this virus, and have about a 50 percent chance of having a child with AIDS. The problem is going to spread.

Other areas of the country discussed so for are not as affected as we are. But if drug use continues, the spread of this virus can be expected to find those groups. And then you will have the added problem of having a mother dying of a disease, and the child dying of a disease. And then to provide those additional services, if possible.

My answer to your question is very simple. Education. Somehow, we have got to convince people, and educate people of the dangers of drug use. We have got to somehow, accepting the fact of how difficult the problem is, but not giving in to the defeat that we cannot do anything about them. Educate women about the dangers of getting pregnant if they use drugs. At least in New Jersey and areas where there is AIDS. And certainly, that is going to spread.

We would not see a pediatric AIDS case, if women who were abusing drugs would avoid pregnancy. At least until we know more about this disease, and can do something about it.

How many times have you seen educational programs geared to that fact? You have seen lots of programs about keeping 8-year-old children out of school, because we do not want AIDS to spread that way. We know very well from medical facts that is not how AIDS is going to spread. But have you seen one program talking about the issues of avoiding pregnancy if you are a drug user, or you are married to a drug user? And my answer to that is you have not seen it.

I think people feel that you cannot educate the drug using community. I have been in Newark my whole career. And that may be true that there are a lot of difficulties in educating the drug using community. However, I do not think we should give up.

I think the major focus of a lot of programs has to be on that educational message. Some way we have to support those programs that, in fact, deal with the drug users, to get that message across. I do not know how you do it. That is not my area of expertise. But that is the answer to your question.

Actually, it is a very simple answer to your question. Doing it is a little bit harder.

I would also say, thought, that I would hope that, in your drive to prevent these processes that we have been talking about, you do not forget about the ongoing need. One of the problems with AIDS has been that, I think, people have said, well, we have some AIDS patients, they are going to die. Let us forget about them.

We have a lot of children we have to take care of. And I think we have turned our backs on the AIDS victims. We have expected them to all die and go away. But they are not all dying. And they are not all going away. And the problem is there. And we have got to start providing services for them.

So, yes. We have got to provide educational services to prevent AIDS, prevent all the complications of substance abuse.

There are also a lot of people out there who are sick. Both with substance abuse, and now with AIDS. And we have got to do something for them to. And I think we ought to direct our efforts toward that, because there are a lot of children, and there are a lot of women, and a lot of mothers suffering the terrible cost of drug abuse.

Again, as I started off my discussion, in 1972, I was so impressed as a young doctor, what a horrible thing drug use did to children and to women. Now, in 1986, I realize that that horror was only half of what it really is, now with the introduction of AIDS. I think we have really got to start making an effort.

I do not mean to keep hounding this issue home, but it is a most important issue. I do not think we have recognized what the problem is. I do not think we have realized how severe it is. Certainly, we have not begun to apply the mechanisms to address those questions.

Nothing right now is being done for the drug using women, and the child who develops AIDS because of that process; nothing.

Chairman MILLER. Will the gentleman yield on that point?

You know, it is very difficult to get people in our position—policymakers and politicians—to embrace the notion of education. Because there is not a lot of public appeal in that.

But in the factsheet that we have prepared, and I think these facts in part are actually from a previous hearing that we had on fetal alcohol syndrome, we note that 30 percent of the mothers who drank prior to pregnancy but were then informed about the detrimental effects of drinking, stopped. Even heavy drinkers stopped drinking during that pregnancy.

Thirty percent of a million represents 300,000 people. It is not the perfect goal, but it does show that people who are abusing substances can be educated as to that detrimental effect. If you start to place a value on the fetus and on the newborn infant, you start to see a change in behavior, at least through most of the studies, that we see. Whether it is 15 percent or 25 percent who stop smoking, 30 percent who may stop drinking, it does appear that if you do it in a first-rate fashion, you can reach and start to change some of that behavior.

I will not suggest that you can change all of it. But it is hard to get the Congress or any legislative group to say education is where we should put our money. Or rather, it appears, more advantageous to put it in a more dramatic program, perhaps more expensive but not as successful. Ms. Finsterbusch?

Ms. **Finsterbusch**. I would just like to agree with you totally, in terms of education as a method of prevention.

I do not think it is an accident or a coincidence that in all of the years that I have worked in substance abuse, I had never seen a pregnant woman entering treatment until the Women's Center opened, and the first two clients who contacted us were both pregnant.

I see that as being a direct result of the public education around FAS—fetal alcohol syndrome. In both cases women had become aware through efforts in public education of the risk to the fetus. Attempting to stop drinking, they found they were unable to, and sought professional help.

I think that, in itself, is testimony, really, to the efficacy of public education, as prevention, in terms of drug abuse. With alcoholism, I think it is a little different. I am not sure that there is any possibility of absolute prevention of alcoholism, because there is such a strong genetic factor in the etiology of the disease. I just believe, on the basis of what I have seen, and in clinical experience, that there are people who have such a strong genetic predisposition that if they drink at all, they will develop addiction to the drug alcohol.

This is a society in which people drink. There is nothing abnormal or deviant about starting to drink, at some point, during adolescence or early adulthood. But there are some people who, if they drink at all, are doomed to develop the disease of alcoholism. I do not know that that can be prevented.

But I think women can be taught that if they wish to, and there is any possibility of their bearing children that they need to abstain completely from alcohol.

Chairman **Miller**. Dr. Chasnoff?

Dr. **Chasnoff**. I would like to address that last point. The information that alcoholism or drug addiction is genetic is not really clear. We are not able to disassociate the effects of the environment in which a child is raised, as opposed to the real genetics. There is no genetic marker we can look for.

There are some studies that we are presently doing, to look, to see if there is something that chemically predisposes a person to become alcoholic or chemically dependent, but those things are really not complete. I do not think that there is any researcher who will say that he has been shown conclusively that there is a true genetic aspect of alcoholism.

The other factor is that, when we speak of education, we speak of rational thought. And many women, and many men, who are addicted, are not capable of taking rational information and converting that rational information to personal policy.

More than pure education, I think we have to begin changing attitudes in this country. Changing attitudes means looking at the way we live our lives: public figures, rock stars, movie stars, politicians—we have to begin setting examples for children when they are young that alcohol——

We know that public attitudes—whether a person uses drugs or not, it is his attitude toward drugs that is communicated to children, to pregnant women. So that it is not just the fact of going out and having a drink in a social situation. It is how you utilize that drink to entertain yourself and to entertain other people.

This is the job that we have in front of us. In some of the schools that I work with in Chicago, we begin education programs in the fifth grade. Now, we are talking about more of a middle-class population in these schools, so these children are not specifically exposed to the hazards that were mentioned earlier——

Chairman MILLER. If I can interrupt you, let me ask you a question.

There is no question, if you are dealing with the serious, habitual drug user—your problems, in terms of education, to overcome that behavior as related to pregnancy, as we were talking about this morning, are very difficult. But just what level—or what percentage of women are we talking about, who are simply ignorant of the relationship between smoking, drinking, at moderate levels? Women who drink a couple of drinks a day, or smoke a couple of cigarettes—because what we are seeing in the research is that low levels of use produce some detrimental effects. Not all low level does, but in some cases where we are not talking about heavy drinkers, where we are not talking about the thought process being impaired. There appears to be some relationship there, simply of the ignorance of the transferance of the chemicals to the fetus.

Dr. CHASNOFF. I think there are very few individuals in the United States who do not realize that cigarettes and alcohol cause problems during pregnancy. I think that that has been demonstrated. Whether those individuals can apply it to themselves has not been shown.

Now, I realize you have cited some studies. But when you look at the studies of pregnant women changing their habits during—once they become pregnant, that data is not really clear. It has been shown in several other studies—some studies that were done up in Canada by Peter Fried, that women do not really change their drug use patterns during pregnancy——

Chairman MILLER. What happens in your program?

Dr. **Chasnoff**. Well, because of the intervention they do. I mean, that is one of the goals.

Chairman **Miller**. OK.

Dr. **Chasnoff**. OK. So, you were asking education, or you were asking for intervention before a woman becomes pregnant. We are talking about substantive preventive programs.

Once a woman becomes pregnant, I really think it is too late to change everything in that 9 months, so that the baby comes out fine, because there are going to be some effects. We have to reach women and men, before they contemplate having children.

We have also ignored men in this whole issue as we have talked today. We know, from several studies, that a man's use of——

Chairman **Miller**. Congresswoman Lindy Boggs has——

Dr. **Chasnoff**. You shake yes——

Chairman **Miller**. She has got a series of questions——

Dr. **Chasnoff**. That is all right. Do you mind if we talk about men for a minute? We know that in opiate users, such as heroin and methadone, that a man can take his drug, and we find levels of the heroin and methadone in his semen.

Now, at this point, it appears to have a major effect on his fertility, in that there are fewer sperm produced. And the sperm that are produced are less mobile, or motile. In human studies, there is no evidence that that directly affects the outcome of the child, if he does conceive.

There is evidence in animals, that the baby rats born to a father who has been exposed to the drug are smaller, and the litter sizes are smaller, and this kind of thing, but this has not been shown in humans.

We certainly know that a man who is abusing drugs has an effect on the woman. His mate. And his effect on her, certainly has an effect on how she interacts with the child.

So we know there is a role of the father in all of this. If not biologic, certainly psychologic.

Mr. **Coats**. Yeah——

Ms. **Thomas**. I think the problem also has been, not only in dealing with the actual pregnancy issue. But again, after children are born, and are born physically OK, we are seeing large numbers of children who are brought to our emergency room, and parents do not realize their judgment has been impaired, until they start to come out of it.

I have stood over too many families, grieving over the dying child, and subsequently are facing issues of homicide, when they say,"I have killed my child." Their intent is certainly very different, as they are coming out of the drug, as opposed to when they were heavily involved in the drug, and bashed the child, out of emotion.

So, we are looking at both ends of the continuum, because just a guarantee of avoiding the pregnancy, when there are children in the home when there are problems of substance abuse, we are really walking on a time bomb of issues. Those issues are the kinds of things that require services, both at the preventive level, but clearly at the intervention level.

Emergency rooms are overwhelmed with these kinds of families who are very, very difficult, really, to work with at that time.

Mr. Coats. Jenny, if I could just ask you one last question.

You have heard us all talk about prevention, and the need for education at younger and younger levels. What would have made a difference for you. If somebody had told you in second grade, or fifth grade, or if you had a class in eighth grade?

You know, I am reminded of the line in the Bruce Springsteen song—I should not admit it as a conservative Republican that I like Bruce Springsteen. [Laughter.]

But there is a line in one of his song that says, we learn more in a 3-minute record than we ever learned in school. And that gets to Dr. Chasnoff's point about society's attitudes and our role models.

What do you think would have made a difference for you, if anything? Would a teacher standing up telling you that drug addiction is bad and it might harm a child, or you should not have sex if you are on drugs, because you might end up having a baby, or you might forget to use prevention. Would that have made a difference?

Ms. Custis. It did not. I had speakers come to my junior high school classes, and my high school classes, in health usually. They had films, and different things. And this was before I started getting high, and during the time I started getting high.

I was under a lot of emotional stress, too. A little more abnormal than most people, I am sure.

But I think, basically, that if I had seen the results of what happened after a baby was born, or if more people were willing to get up and speak and tell their stories—it is different having a teacher tell you something, or a doctor, or your mother, than it is to hear it from somebody else's—from the horse's mouth, as they say. I think I would have listened a lot better.

Now, we had one speaker, but it had nothing to do—that used—but it had nothing to do with pregnancies and other such things.

There just—people are not willing to get up and admit these things in front of people. And I think there should be more.

Mr. Coats. But in addition to the knowledge, and maybe hearing from people your own age—people that have been through the experience, I think you just said, you needed to deal with the emotional problems, too.

Ms. Custis. Yes.

Mr. Coats. You had some problems that you were trying to deal with, in terms of family, and acceptance and love, and so forth. That has to be part of the solution, too, does it not?

Ms. Custis. Big part. And it has a lot to do with it.

That is—I was not getting support, because I was not telling anybody what my problem was. I did not want anybody to know. I hid. I ran. I saw what happened to my mother when she was using, so I knew better than to go to my family, or to a doctor.

I just was afraid that they would force me to get help. And I wanted to do it on my own. It had to be—I had to hit rock bottom, almost, in order for me to see the light. I had to drug and drink myself to the point of getting sick all the time, and waking up with hangovers, and getting tired of it.

But as far as education is concerned, it is very important that, along with the education, that you have somebody that you can rely on, like Meredith, for example, who is there with the love, with the understanding, in that kind of sense. Because without that support of the Women's Center, and the self-help group—they are all very loving people, and understanding. They have been there. They understand.

I would not have made it. There is no way.

Mr. COATS. Do you think if that love and support and understanding might have been available to you, in some form, before you got addicted, that this might have helped prevent you getting into that?

Ms. CUSTIS. Well, if I had told somebody I had had a problem, I believe my family might have come around with some love and support. But it would have been a forcible, forceful type support. They would have been saying "you go get help or they would have yelled at me and screamed at me, and approached it in a totally different manner than the way it was approached to me later on through the program.

Mr. COATS. OK, but what I am saying is if the right kind of support had been present, could it have helped prevent you from turning to that as an alternative, because you knew if you went to your parents you would get the kind of reinforcement or support or help that you needed?

Ms. CUSTIS. Definitely.

Chairman MILLER. Lindy.

Mrs. BOGGS. Thank you, Mr. Chairman. Thank all of you very, very much.

I have been enormously impressed with the loving and caring attitudes of the great professionals. It is very heartwarming to all of us, and it should be to you, Ms. Custis, because you know that that is the ingredient that is most needed in the treatment.

When we are talking about education, I think we should also look to the kind of education that Ms. Thomas and Children's Hospital provides. Because it is really educating the care agency personnel. It is educating the law enforcement personnel. It is educating all of the persons who are involved in the private agencies and organizations and community advocacy groups. What has been done here at Children's Hospital to coordinate, the Mayor's Committee that is made up of some 30-odd private organizations, and the D.C. Department of Health Services, and the D.C. Schools, and the D.C. Police Department, and the U.S. Attorney Incorporation Council, and the D.C. Superior Court, Social Services, and the Maryland Department of Social Services, and the Virginia Department of Welfare—to coordinate the activities of all of these groups, and to educate those experts in prevention and care. Recognizing, that these are all of the areas that are necessary to stop intergenerational difficulties, to rescue the children, and to certainly, treat the parents.

So, I think the educational activities have to extend far beyond the education of the parents. And I think parents should be emphasized, because we have to educate boys and young men, as well as the young women who are responsible for childbearing.

I wondered, Ms. Custis, if you know what has happened to your father? If you know whether or not he is a drug or alcohol abuser?

Mrs. **Custis.** I do know where my father is at. He has never used drugs. I believe he used to drink mildly. And he claimed that it made him mean, so he stopped drinking.

Mrs. **Boggs.** And your brother, has he been affected?

Mrs. **Custis.** Yes; my brother went to Nam. And we all know the story about the drugs over there. I am not sure what he was involved in, but I remember a lot of drugs when I was little, and watching the kids that hung around.

I remember running across drugs in his room, and I remember some of the stories that he told my parents, about him being a narc, and that he had evidence baggies full of stuff. And it definitely was not evidence baggies.

Mrs. **Boggs.** Dr. Oleske, I was so very interested in your testimony, and extraordinarily grateful that someone with your expert knowledge, and your caring, is involved in the AIDS problem.

You have said that there are no Federal funds for health care for AIDS. That the Federal dollars are mostly research. I know that the idea of putting a lot of Federal dollars into research was to try to find some type of cure or prevention—preventive kind of inoculations, before AIDS became a terrible national epidemic.

For instance, we have heard that you can take a shot of penicillin and cure a case of syphilis. Think of the years that went into the research that discovered that kind of a cure for what was a national difficulty.

What kind of Federal dollars do you think we should put into the health care for AIDS patients?

Dr. **Oleske.** I understand the dilemma. The problem is that the epidemic is already here, and that we are still maybe 10 years away—maybe 5 years—from a preventive vaccine.

I cannot really answer what are the necessary dollars. I can only tell you that I know that the dollars so far put in, are not enough, certainly, to provide services to patients.

I have no objection, by the way—in fact, I am very supportive of research care dollars, and have participated with the NIH in getting them proper specimens from our patients so that they isolate the virus. And I think that is all very important.

The point is we have a very rich society that I think certainly can afford to provide also care services to patients. Maybe that will change in the future. But right now, as of 1986, very precious few dollars go to AIDS care.

To give the numbers, there is a proposal now, I guess, of almost $200 million to go into AIDS endeavors. That has not yet been spent, and has not yet been allocated. Clearly, about—approximately $20 million has been, I think, given so far to AIDS.

The care of one AIDS child in the hospital is overwhelming on their children's hospital. I am sure the people here at Children's Hospital who have one of those—our hospital in Newark, NJ, Children's Hospital, just about went belly-up, trying to take care of these children. They spent $186,000 in just IV gamma globulin alone, a medicine we give just once a month.

The care costs are horrendous. And no one wants to pay it. The problem with AIDS and patients with AIDS is that no one knows what to do about it.

We knew that we had to provide research dollars to get to the root cause of it, and to provide prevention. That is all well and good. The problem was, we never really had an epidemic of the proportions of AIDS before. And I think everyone assumed that either Medicaid or Medicare, or Blue Cross or Blue Shield, or Travellers, that someone was going to pick up the care costs of the patients. Well, that never really happened.

And the extensive comprehensive care costs that are needed, the social problems—it is hard to explain. But we have trouble even getting an ambulance to take a sick child to the hospital, because they do not want to take an AIDS patient. And we have to have the ability to argue with them, and to convince them. And there are people who do that, and the social workers—so that the problem is very large. And the amounts put into programs are very small.

Now, I do not—I cannot speak for other programs. I know there is a major program in Miami, with Dr. Gwen Scott. There is a major program in New York. And we have our program in Newark, New Jersey. I can speak for our program. We have not received the kind—any kind of support from the Federal Government, for care dollars for patients. And we have done it, if you will, catch-as-catch-can. And we have built a house of cards in a program that has, for example, a nurse working full time who is only paid half time.

That is how we have responded to it. We have just done the best job we could, with the limited resources.

I think $200 million is a travesty. I never realized, by the way, how much $1 million was, until I got involved in looking at Federal budgets. Only because I was interested in how much was put into health care.

I did not know—as a doctor, I should have known, I guess—that $1 billion was $1,000 million. You know, I think there are a lot of people in this room that probably think $20 million is close to—excuse me—$200 million is close to $20 billion—$20 billion is an awful lot more money. And——

[Laughter.]

Dr. **Oleske**. If you look at right now what we spend—if $1 billion was $1. If $1 billion equals $1, then we are paying about 20 cents for AIDS research in 1986.

If we go to build that nuclear aircraft carrier, we are paying about $20.

If you look at the regular budget, I guess it is $1 trillion? That even comes——

Chairman **Miller**. We will not admit to that——

Dr. **Oleske**. Well, if it is $1 trillion, you are going to get—out of that $1 trillion, you are spending, all the services you want to provide to us citizens. Out of that $1 trillion you are going to give one-fifth of 1 cent toward AIDS work.

Let me tell you, you are dealing with a major health crisis facing this country right now. And you are giving one-fifth of 1 cent.

So, is that appropriate? I do not think so. You people may think that is appropriate. You may decide that the nuclear aircraft carrier cash-flows through—the 50th one—is more necessary, and that more Americans are going to die if we do not build that, than if we put an effort into AIDS research.

If I may just digress one second. When Kennedy said he will land a man on the Moon, he was able to do that, because he knew he had the technical resources to put a man on the Moon. And if he committed enough moneys to it he could accomplish that task.

If he had said, I am going to land a man on Alpha Centauri, another star, no matter how much moneys we put into it, we could not have done it.

We are at the same story with AIDS. We have the technical know-how. We know what the virus is. That we could, in fact, eradicate this disease. We actually could probably eradicate a lot of other diseases. But we could eradicate this one. This is the one we are talking about.

If someone made the commitment that in the next 8 or 10 years, we are going to eradicate it, and commit the resources necessary to do that—we have the technical skills. We are not even coming close to committing the technical resources.

If you ask me to give you a number, I will give you a number; yes. Give us an aircraft carrier. Give us—$20 billion.

[Applause.]

Mrs. **Boggs**. Doctor, you say that 20 percent of the mothers die——

Dr. **Oleske**. At least 20 percent.

Mrs. **Boggs**. What happens to the children of those mothers?

Dr. **Oleske**. Well, in Newark, we have been fortunate to be able to talk to other family members, and find, usually grandmothers, who would take over the care of the child. We have some problems with—we have some problem with foster care, but I have fallen in love again with grandmothers, because they are an important resource in our society——

Mrs. **Boggs**. They do so much. [Laughter.]

Dr. **Oleske**. So, a lot of our children are cared for by those individuals. The sad part of AIDS is when the mother is still alive and trying to take care of her child. And that is a struggle.

She is sick. She recognizes what has happened. And also, she has tremendous troubles with her own guilt, because you can imagine what she feels. I have done this to myself, and I have done this to my child.

We have seen, in our drug-using community now, about half of the children born to a drug user who has this virus develop the disease. And 20 percent of those die.

So, I say to my colleagues in other drug using programs, if your virus is not there yet, and is introduced, that is the tragedy you are going to have to add to all the other problems you have.

I mean, all these other problems they are talking about—prematurity, sudden infant death—you are going to have to add into that equation another major problem. And it is going to be substantial if we allow this virus to spread into that population.

Ms. **Thomas**. I think that point should be emphasized because we are beginning to see that increase, at least in the social welfare system of the real problems, first of all, of finding placement for these special needs children. And I also would support the—certainly extended family responsibility.

But many times, there is not an extended family. And many times, the extended family, also, is not capable. And I would certainly want to emphasize, really, the long-term effects for these children, in terms of safe homes and caring homes, this just could not be minimized.

We are already at the limits of our ability to find adequate homes for these youngsters with other problems. And this is going to be an added problem——

Dr. **Oleske**. Well, respite care is an area that needs to be considered. The Ronald McDonald houses are a nice concept, that is a voluntary effort. But there may be—there probably is a need for more formalized, federally supported respite care for these individuals.

Mrs. **Boggs**. Thank you. I know that Mr. Walker knows the value of grandfathers, as well, with the programs that he has at the Odyssey Parental Program. And I feel very strongly that we must involve the boys, the young men, the men, in all of the areas of education, treatment, and of learning to break generational difficulties for their children or their grandchildren, and to be healthy, emotionally and physically themselves.

But I have many, many other questions that I would like to ask. I get terribly worried, for instance, about the children who leave the ICU Program. What happens to their care between the time that they leave there and the time that they are able to go to preschool, or are able to get into some other program where health care is provided?

But I would just like to end, Dr. Chasnoff, with thanking you very much for combining your brilliance and your expert knowledge of medicine and science with a very caring and loving attitude. And I would like to tell you that when my son was tiny, I felt very badly about talking down to him. So, I sought out the safest place in our home, and decided it was a huge old dining room table.

And so, I would place him on the table, and I would pull up the chair, so we could talk, eyeball to eyeball. And suddenly, one day when he was 11, I found myself looking up at him. [Laughter.]

And he sort of had a little smirk on his face. And I said,"Oh, you." And he said, "What do you want me to do, Ma, put you on the dining room table?" [Laughter.]

Thank you very much, Mr. Chairman.

Chairman **Miller**. Thank you.

Dr. Oleske, there is a traditional social service delivery system out there for children, as inadequate as it is, on a day-to-day basis. But what you are telling us, is because of the complication of AIDS that that system simply does not respond, or will not respond. Whether it is out of fear, prejudice, whatever the reasons are, at the moment we are confronted with a nonsystem for these children—and I assume, to the same degree for their parents. Is that right?

Dr. **Oleske**. That is a fair statement; yes.

Chairman **Miller**. We talked a little bit about cost. Regarding the population in Newark, you have knowledge of the individual circumstances there. What are we talking about, to provide the kind of care that we should, in a humane fashion, for these people? How do you develop the resources?

Dr. **Oleske**. First of all, the resources that are already supposed to be there and committed should be utilized. And we should somehow find a way, I guess, of enforcing that. But Medicare and Medicaid, and other—Social Security somehow just do not provide the services they are supposed to.

I guess one of the things we should do is convince those agencies and programs to redefine how they fulfill their committment.

I think that one thing AIDS taught me, besides a lot of humility, in the frustration of not being able to treat people was that, as a country, I guess we do not know how to respond to an epidemic. Our agencies, the NIH and the CDC, and in a small way, the Federal Drug Administration—the FDA—are really not geared to handle a problem that is emergent and rapidly progressing.

They do not have the—I guess the charge to do it. And I am not sure what the answer is. But clearly, we should learn, and look back on what happened with AIDS, and maybe redefine what is the role of the NIH. Is it only pure research? Are they just supposed to buy chrome and equipment? Should they get involved in direct patient care services? Right now they are not.

The Center for Disease Control is an epidemiological branch. It collects facts and data. It tells us how bad the problem is. It does not do anything about the problem. Should they, in fact, be involved in that?

The FDA is involved in limiting drugs, so that they do not hurt our population. Yet, what has happened with AIDS has been a stifling of trying to get drugs, through a terrible disease that is rapidly progressing, we cannot use the drugs.

Just a sideline on the FDA—we just got permission and just to tell you the dilemma—finally, after about 1 year of struggle to get approval to use a drug, an antiviral, in children with AIDS. It took us a while to convince the company that made it. They did not want to get involved in the treatment of children. Because you have to understand—it is bad enough treating adults. But to treat children, even though they are dying just as quick, is a problem for them. Because the usual mechanism, which is ponderous and slow, we do drug trials in adults, phase 1, phase 2. And if adults have limited toxicities, then you try it in children.

Well, right now, with the AIDS epidemic, we should not be going by those rules. But we are trying to follow the rules.

So, the drug company did not want to give us the drug. They finally agreed, after 1 year, to give us the drug.

So, now we have the drug, and now we have the FDA-approved program—they like our way of giving it, they think it is safe, go ahead and do it.

But the problem is, to give that drug, we have to monitor certain things. We have to give certain care to these children. We have no resources to provide this care.

So right now, in Newark, NJ, I have a drug that probably is not the cure for AIDS, but it is a start. In other words, we are getting away from just symptomatic care, and getting involved in looking at maybe new drugs that may help children.

We have got approval to use it, but we cannot go ahead and use it, because we do not have the resources to pay for the tests, the laboratory studies, et cetera, that you have to do to meet that protocol.

Should there be another agency that is geared to rapidly respond to an epidemic that has a group of funds that can be rapidly disseminated? But the problem is, I do not know.

But clearly, the system we have right now has not been able to respond to a disease like AIDS. And I do not think AIDS is so unique.

There is going to be other diseases coming down the road in the years to come, like AIDS, as we move agrarian economies into urban areas—as a jet plane flies all over the world, we are going to be mixing viruses and other infectious agents.

And I think now is the time to take stock of how we respond as a country to a problem like this, and empower somebody—some agency—with the ability to respond a little bit better than we did with AIDS.

Mr. Coats. Would the gentleman yield on this point?

Chairman Miller. Sure.

Mr. Coats. Dr. Oleske, I appreciate what you are saying. However, one of the things we are dealing with in Congress, at least in the public's mind, is that there is a distinction between AIDS and other diseases that affect society.

It is not so much a question of trading an aircraft carrier for $20 billion for AIDS research. It is a public perception, based on some reality, that the victims of AIDS are victims of their own choosing. That AIDS is primarily the result of homosexuality, prostitution, and drug use. And that there are a lot of people out in society, who question whether it is right or wrong, why they should use their tax dollars to treat the consequences of those acts, when, if those engaged in such acts would simply stop doing it, we could solve the problem. Or we would not have the problem.

Now, I understand that there are victims of these consequences that, through no involvement of their own, have the disease. And I would also hope that we are the kind of society where we show love and compassion to those that are engaged in activities that, perhaps we do not agree with, and suffer consequences from it.

But I think that we have to be realistic, at least I do, when I go back home and try to explain why we are spending money for certain things, whether it is an aircraft carrier or AIDS treatment, realistic, in what the public's perception of this problem is.

And I think when we are talking about AIDS, we are talking about a disease that, at least in the public's mind, is separated from other diseases that affect the general public as a whole. Because many people see this as something that could be cured, or would not have happened in the first place, without individuals engaging in illegal or other acts that a lot of society feels are abnormal.

Ms. Thomas. I think if we look at it from a simplistic point of view, and put things in categories, that would be the public's perception.

But when we look at the volume—the impact on the social welfare system, the implications toward child maltreatment—the issues in terms of hospital costs which, again, will hit the public—I think that we have to look at it more comprehensively. And I do think that the problems, not only in dealing with AIDS, certainly are similar to dealing with other problems.

There are coordinating problems. Getting people together to problem-solve is difficult. It costs money. And no one really identifies where those funds are coming from.

I think if we continue to use the fee-for-service model to just, really, put a bandaid on that particular diagnosis, and think that is going to resolve it, I will tell you that it will not.

Most of the costs associated with trying to combat all of these issues that affect children, of trying to work with professionals and nonprofessionals, to really understand the problem at a variety of levels. And AIDS is adding to that problem. There is much uncertainly—we are not seeing the high volumes that they are having in other communities. But we have the high drug population. We have the enormous social welfare problems already. And we cannot single out one being worse than the other at this point in time, because we really can't see it.

The coordination effort is never really financed by anyone. And the process of trying to get one agency even to listen to another, is hours and hours and hours of time. And the benefit to one child—a benefit to a lot of children is what we really must focus on. This is our goal.

And I think if the public really had some concerns about the broader issues, and understands the broader issues—I can understand the problems in attempting to attach a dollar amount to such a problem. But I think that has been our problem. And I think if we can really try to look a little broader, at the needs of children, and the implications, as a whole, we can begin to really get the support of the American public.

No one wants to see children hurt. And I think one trip to the ICU, and one trip to the other unit to hospitalized children will convince one of the gravity of the problem. I could have brought gory slides of all kinds of burns and injuries, and it would shock and impress this audience. We must understand that these problems are often based on a long history of suffering within families, and by individuals who—we cannot legitimately blame them alone and hope that is going to solve the problem. Because they, substance abusing parents, are not even listening. They are in another level of understanding.

And we are attempting to cope with the results, and it is becoming overwhelming.

Mr. **Walker**. Are we repeating history where, in the 1960's, you used to say that drug addiction was a local problem, it was just a minority problem, or a poverty problem? Are we repeating history by saying that it is the same thing with AIDS, and wait until it hits the middle class and the rest of the population before we deal with it?

Dr. **Oleske**. Let me give you a scenario. People always ask me that same question. Well, first of all, the children, I think, are the innocent. And all the spouses of previous drug users are certainly innocent. But do we even count those numbers?

The story is, going to be the guy from Prairie View, TX who is 18 years old and is drafted into the Army, and he goes to—I am making this all up—he goes to Germany, and he sows a little—few wild oats. We may accept that. We all turn our back on that. We do not accept homosexual behavior, but we would accept him going with a prostitute, say.

He maybe uses a little drugs, but he is really not a bad person. He goes back to Prairie View, TX, becomes a born-again Christian, and an elder in his church. He marries his childhood sweetheart, and lo, and behold, they have a child with AIDS.

And that is the insidious nature of AIDS. Remember, 80 percent of women who have children with AIDS are well. A good number of fathers who father children with AIDS, infect their wives, and are healthy, when they have a child dying of AIDS.

And so, that story I just outlined for you—and that person, by the way, I do not think would be considered very far from the norm of what our society is really like, is going to be how AIDS spreads, if you will.

It is not going to spread because of the workplaces. It is not going to be spread because you sit next to me, or you go to school with a child. But it is going to spread by those mechanisms.

But that story is not uncommon. That little scenario I said, goes on all the time, every day. And so that, I think we have got to wake up, if you will, that AIDS is not just a disease of poverty. Right now it is, maybe, and it is in certain populations. But it is a disease that threatens us all. And if it threatens the least of our brothers, it threatens us.

And I think—you know, you guys are really putting pittance into it. You know, you are putting in one-fourth of 1 cent. And yeah, we do need an aircraft carrier. But someone is going to have to wake up to that fact. And maybe they will wake up to that fact when their neighbor, or their friend, or their brother has AIDS.

And it is a shame that we have to, I guess, work on that level of sensitization, in that we cannot do it a little bit preventively, so that we could prevent some of the tragedies that we have seen.

Newark, NJ, may be the start. But it is going to go to Tulsa, AZ. It is going to go to—and I am sorry I do not know the state you are from—but even North Dakota is going to get a little AIDS, and that is a shame. And you should stop it now.

I would love to see no other State, no other city—I would love to see no other pediatrician have to go through the tragedy that I have had to go through.

It is not funny, taking care of children, many of whom die. Especially when you went into pediatrics because you love kids, and you did not want to see anybody die. It is a very, very, sobering experience. A very humbling experience.

And that is maybe why I sometimes get angry at things like this. You have to understand, if you work every day up in Newark, and saw what we saw, you would come down here for a conference like this, and get a little angry.

You want people to listen. We want you to know about the problem. We would like you to do something about the problem.

You guys write the checks. We just take care of the patients.

[Applause.]

Chairman MILLER. If we are going to start distinguishing whether or not we are going to deliver care based on whether there are self-inflicted wounds involved, groups like the American Cancer Society will have a great deal of trouble raising money. Millions of Americans need care due to self-inflicted wounds, whether it is alcohol, tobacco, or what have you. We still care for them. But I think that what Congressman Coats points out is a problem of perception regarding AIDS victims that is very real in the Congress of the United States.

Some people think you deal with the AIDS problem by making it a felony. And then people will not get it. But as you clearly point out, Dr. Oleske, and other panels have, to other committees, that to ignore this problem, or to think that we are going to get by on the cheap, is a grave mistake. One of the very cruel tricks that we would play on our constituents would be to imply that by condemning AIDS, we are going to insulate our constituents from the tragedy.

Because, as you have already pointed out, there is an awful lot of evidence that the insidious nature of AIDS is going to work its way through each and every community, if we do not do something in a rather effective fashion pretty quickly.

Let me thank all of the members of the panel for your time, your expertise. I think it has just been very, very, helpful to us. I think, once again, this panel helps us in making policy, whether we want to buy in in terms of prevention, as Congressman Coats pointed out, or whether we simply want to pay the bills for the failures. There are opportunities for success in intervention and prevention strategies with this very vulnerable population so that we do not have infants who, through no fault of their own, find themselves in a terrible amount of trouble at the very beginning of their lives. I think we have learned that much this morning.

So, I want to thank you again, and Children's Hospital.

The committee is going to take a 3- to 5-minute break, here, to give everybody a rest. And then we will start with the second panel. And if members of the second panel would just come up when they are ready, then we will start right away.

[Whereupon, a short recess was taken.]

Chairman **Miller**. The select committee will come back to order.

I think it is clear to everyone in the room that this subject is one of deep concern to the members of the committee, from the time that we just spent on the first panel.

Let me explain that Congressman Coats and Congresswoman Boggs are both very, very much involved in the trade bill that is on the floor in a few minutes, and had to leave for there. I will continue the hearing. And we have some time problem but let us just get through here, and make sure that everybody is heard in proper fashion.

On this panel we will first hear from Dr. Lawrence Fenton, who is a professor of pediatrics, at the school of medicine, the University of South Dakota, in Sioux Falls, SD. He is accompanied by Dr. Ann Wilson, who is the associate professor of the department of pediatrics at the university.

STATEMENT OF DR. LAWRENCE FENTON, PROFESSOR OF PEDIATRICS, SCHOOL OF MEDICINE, UNIVERSITY OF SOUTH DAKOTA, ACCOMPANIED BY ANN WILSON, PH.D., ASSOCIATE PROFESSOR OF PEDIATRICS

Dr. FENTON. Ann will begin our testimony.

Chairman MILLER. OK.

Dr. WILSON. Mr. Miller, being here today——

Chairman MILLER. Do you have proper lighting?

Dr. WILSON. To be here today, and to contribute to the important discussion of high risk babies is, indeed, a privilege. Our goals are to share with this committee our view on the subject from very fundamental perspective on the problems that have been discussed this morning.

We will discuss how a baby develops the capacity to experience the feelings of attachment, so critical for survival and emotional well-being. Then we will approach the problem from the standpoint of the physician at the baby's bedside and finally, attempt to place the data you have heard within a context of overall values in our American way of life. We will begin by giving a discussion of human attachments.

Like life itself, attachments emerge in a cycle, with any one person connected to older generations, younger generations, and generations yet to come. Yet, the natural beginning point for understanding the development of human attachments is with a new baby.

In order to survive, a baby is obviously dependent on being cared for by others. However, care which provides food and hygiene alone does not create an environment sufficient for growth in its fullest sense. To develop the capacity to experience the emotions of warmth and love, a baby must experience a special closeness and a sense of belonging to his or her parents.

Indeed, this all begins before birth. During the months of pregnancy, a growing fetus is dependent upon the nurture of his or her prenatal environment. Geneticists and developmental psychologists alike, will readily agree that from the moment of conception, the emerging organism is affected by environmental influences, which will endow or destroy future capabilities. A mother's investment in her growing, yet unborn baby, is the beginning investment which will nurture the child's future capacity to relate to her as the most important and special person in his or her world.

Attachment can be seen in a baby's contentment, when cuddled by its mother and in the effervescent joy of a young child reunited with parents, following a brief separation. Positive attachments bind families together for generations, while thwarted attachments can provoke the angriest and most violent of behavior.

When human attachments have not been formed as a child, love cannot be experienced as an adult. Prof. Selma Fraiberg, noted child psychoanalyst, observed that the distinguishing characteristic of nonattachment is the inability of a person to form a human bond of closeness with another. Such unfortunate people have an impoverished emotional range. Professor Fraiberg described those with no attachments as remote and experiencing no joy, no grief, no remorse, and no guilt.

Freud was once asked what he felt all adults should do well. Expecting a deep and complex response, the questionner was surprised when Freud simply replied, "to love and work." Can we think of a society where its members all could love and work? Would not many of the ills which plague us as a Nation be minimized if those capabilities were within the range of us all? If all citizens could experience productive work and meaningful, loving relationships, we would probably all agree that there would be less pain, less anguish, less expense, and less unnecessary labor for us as a national and world community.

In thinking about Freud's statement, of importance is that he put love before work. Indeed, the ability to love precedes the ability to work. The capacity to experience affection and to give affection, to share closeness and intimacy, to feel secure and safe, are very basic foundations for human growth and fulfillment. This is essential, not only for survival in its fullest sense, but also for the ability to nurture a baby—even a baby that is yet to be born.

To love requires, at times, that the other's needs be put before one's own. Certainly, during pregnancy, a loving mother who is becoming attached to her baby is eager to make the best beginnings for this new life even when this means her own needs are put aside for the next generation whose care she is fostering. It is this which is missing when a mother places her infant at risk by her addiction or disease-prone behavior.

Dr. **Fenton**. Mr. Miller, what I would like to do at this point is to bring us into a discussion and portrayal of the everyday realities of patient care.

On a daily basis in the intensive care nursery, we are frequently confronted with sick children whose mothers will come to us and say,

> Well, doctor, I did everything I could. I did not smoke. I did not drink. I exercised appropriately. I did all of the things that I was supposed to do. Why is my baby sick? Why was he born with this defect? Why was he premature?

Indeed, those are hard questions, and represent a particular kind of tragedy in a family whose expectations for a normal, healthy child were shattered, and who look to themselves for reasons why. And though blameless, this type of family assumes guilt for their child's dilemma. And while we recognize that a terrible misfortune has befallen that family, we know that no matter what the problems are, parents with those attitudes tend to provide a caring, nurturing, and loving environment for their child.

Now let us walk through a 180 degree turnabout, when a physician is confronted with an infant of a drug addict or alcoholic. Mark Twain once wrote that we are all like a moon, each with a dark side that is revealed to no one. This is the dark side of medicine, upon which physicians are usually reluctant to place values and judgments, because to state them publicly is to open one's self to ridicule and criticism. Although we try to be nonjudgmental in our approach to a patient's needs and concerns and in our prescriptions and therapies, let me share with you some inner feelings and observations.

To me, a newborn baby is the most wonderful creation and gift of God. He is born innocent, not having asked for the situation in which he finds himself. Although already imprinted with all of the potentials, he yet has no impressions of what life can be like. These impressions will come to shape his feelings and emotions, and will help build a wholeness of personality.

So, in the intensive care nursery, I look down upon this child snuggled in his crib blanket, and I know in my heart that he will be cared for by a mother who does not care. You can say, "oh, well, that is very harsh. Do not say that the mother does not care. She really has feelings and just cannot help herself." Well, that may be, but no matter what the problems of the parents were that led to their utilization of drugs, or to a lifestyle that was disease prone, the result is still a noncaring parent. Whether in her heart she does not care, or whether the realities are that she is unable to care, or whether the realities are that she is on too many drugs to care, or whether the realities are that she is too drunk to care, or whether the realities are that she, too, was so unloved that she cannot care, the outcome is the same for the baby. She does not care. And so we have a baby who is about to grow up in a home in which there is no love. He is lost from the start.

As a fellow at the University of Cincinnati, in neonatology, we looked at our statistics regarding infants of heroin addicts. We knew that by 6 months to 1 year of age, 85 percent of these children would no longer be in their home. We knew that 30 to 40 percent of them would be abused and battered. And we knew that 10 to 15 percent of them would probably be killed. And then you can say, "Well, but we can get them out into foster homes." But that is a terrible solution. As you know, in most States, the child has to be battered before they can be removed from the home. Neglect has to be proven. If you are lucky enough to capture the child before the battering was so great that the child dies from it or is permanently damaged from it, then we may successfully place him—find a home. But the sagas of foster placement heap tragedy upon tragedy. Many foster parents are loving people, but the child still does not have somebody who says, "I will love you unconditionally and no matter what, and you will be mine forever."

Some months after placement, the natural mother may petition and get the child back, only to repeat the cycle. And then the child is placed again, perhaps in a different foster home. Or perhaps the child survives to an age where he has become a behavior problem, and then the foster parent calls the social worker with the message, "I am sorry, we just cannot handle this child. You will have to take him to another facility."

The child grows and learns that there is no such thing as unconditional love. He learns that he can be rejected at will, and nobody need make a permanent commitment to him.

Back to the nursery. I look down upon this child, who is fresh and clean, and I am going to picture the first examination at 4 weeks of age. I can smell the telltale odor of ammonia from unchanged diapers, and unwashed skin. I can picture dirt under the nails of a 12-week-old and the funny little bruises and marks that no one can explain and the flatness of the back of the head, because the child is seldom picked up and the constant, irritable crying of a child, too long without cuddling. As time progresses, there will be the general unresponsiveness of the baby, and sometimes failure to thrive and then perhaps hard evidence of physical abuse.

Mr. Miller, I think you have been listening, not merely to a compilation of facts and figures, but to a scenario of the shredding of the very fabric of society. The toll on human personality is unmeasurable. The further tragedy is the multiplier effect.

These children will pass on their misery to their own children, and to their children's children, and on and on and on. And the larger tragedy is that all of this may be a preventable and unnecessary waste of lives.

The final result is an expanding society of adults who have grown up without love. There is no light side for such people. Their lives are all grays or blacks. Our capacity to love is the enabler of joy, of achievement, of deeds and goals which contribute positively to mankind.

Scriptures teach us to "train up a child in the way that he should go." They teach us "to despise not those little ones, for in Heaven, their angels behold the faces of the Father," because He loves them so.

Therefore, I would ask God's blessing on the efforts of this committee, on behalf of these little ones, whose lives and futures are so important to us all.

And I thank you very much.

[Prepared statement of Dr. Lawrence Fenton and Ann Wilson follows:]

PREPARED STATEMENT OF ANN L. WILSON, PH.D., ASSOCIATE PROFESSOR, DEPARTMENT OF PEDIATRICS, DEPARTMENT OF PSYCHIATRY, SCHOOL OF MEDICINE, UNIVERSITY OF SOUTH DAKOTA, AND LAWRENCE J. FENTON, M.D., PROFESSOR OF PEDIATRICS, HEAD, SECTION OF NEONATAL/PERINATAL MEDICINE, DEPARTMENT OF PEDIATRICS, SCHOOL OF MEDICINE, UNIVERSITY OF S.D.

Mr. Miller, Mr. Coats, and Committee Members:

To be here today and contribute to this important discussion of high-risk babies is indeed a privilege. Our goals are to share with the committee our views on this subject from several perspectives. We will discuss how a baby develops the capacity to experience the feelings of attachment so critical for survival and emotional well-being. Then we will approach the problem from the standpoint of the physician at the bedside and finally attempt to place the data you have heard within the context of overall values in our American way of life.

Like life itself, attachments emerge in a cycle with any one person connected to older generations, younger generations, and generations yet to come. Yet, the natural beginning point for understanding the development of human attachments is with a new baby.

In order to survive, a baby is obviously dependent on being cared for by others. However, care which provides food and hygiene alone does not create an environment sufficient for growth in its fullest sense. To develop the capacity to experience the emotions of warmth and love, a baby must experience a special closeness and sense of belonging to his or her parents.

Indeed, this all begins prior to birth. During the months of pregnancy, a growing fetus is dependent upon the nurture of his or her prenatal environment. Geneticists and developmental psychologists alike will readily agree that from the moment of conception, an emerging organism is affected by environmental influences which will endow or destroy future capabilities. A mother's investment in her growing, yet unborn baby, is the beginning investment which will nurture her child's future capacity to relate to her as the most important and special person in his or her world.

Attachment can be seen in a baby's contentment when cuddled by it's mother and in the effervescent joy of a young child reunited with parents following a brief separation. Positive attachments bind families together for generations. Thwarted attachments can provoke the angriest and most violent of behavior.

When human attachments have not been formed as a child, love cannot be experienced as an adult. Professor Selma Fraiberg, noted child psychoanalyst, observed that the distinguishing characteristic of non-attachment is the inability of a person to form a human bond of closeness with another. Such unfortunate people also have an impoverished emotional range. Professor Fraiberg described those with no attachments as "remote" and "experiencing no joy, no grief, no guilt and no remorse".

Freud was once asked what he felt all adults should do well. Expecting a deep and complex response, the questionner was surprised when Freud simply replied, "to love and to work". Can we think of a society where its members all could love and work. . . Wouldn't many of the ills which plague us as a nation be minimized if these capabilities were within the range of us all? If all citizens could experience productive work and meaningful, loving relationships, we would probably all agree that there would be less pain, less anguish, less expense and less unnecessary labor for us as a national and world community.

In thinking about Freud's statement, of importance is that he put love before work. Indeed, the ability to love preceeds the ability to work. The capacity to experience affection and to give affection, to share closeness and intimacy, to feel secure and safe, are very basic foundations for human growth and fulfillment. This is essential, not only for survival in its fullest sense but also for the ability to nurture a baby - even a baby that is yet to be born.

To love requires, at times, that other's needs be put before one's own. Certainly, during pregnancy, a loving mother who is becoming attached to her baby is eager to make the best beginnings for this new life even when this means her own needs are put aside for the next generation whose care she is fostering. It is this which is missing when a mother places her infant at risk by her addictive or disease-prone behavior.

Let us now bring our discussion into the realities of everyday patient care.

On a daily basis in the Intensive Care Nursery, we are confronted with sick children whose mothers will come to us and say "I did everything I could doctor, I didn't smoke, I didn't drink, I exercised appropriately, I did all of the things that I was supposed to do - why is my baby sick? Why was he born with this defect? Why was he premature?" Indeed, those are hard questions and represent a particular kind of tragedy in a family whose expectations for a normal, healthy child were shattered and who look at themselves for reasons. Though blameless, they assume guilt for their child's dilemma. And while we recognize that a terrible misfortune has befallen that family, we know that no matter what the problems are, parents with those attitudes tend to provide a caring, nurturing and loving environment for their child.

Now let me walk you through a 180° turnabout when a physician is confronted with an infant of a drug addict or alcoholic. Mark Twain once said that we are all like a moon, each with a dark side that is revealed to no one. This is the dark side of medicine upon which physicians are usually reluctant to place values and judgments because to state them publicly is to open one's self to ridicule and criticism. Although we try to be non-judgmental in our approach to a patient's needs and concerns and in our prescriptions and therapies, let me share with you some inner feelings and observations. To me a newborn baby is the most wonderful creation and gift of God. He is born innocent, not having asked for the situation in which he finds himself. Although already imprinted with all of the potentials, he yet has no impressions of what life can be like. These impressions to come will shape his feelings and emotions and will help build a wholeness of personality. So I so look down upon this child snuggled in his crib blanket and I know in my heart that he will be cared for by a mother who doesn't care. You say "Oh, how can you be so harsh; don't say that the mother doesn't care, she really has feelings and just can't help herself". Well, that may be, but no matter what the problems of the parents were that led to their utilization of drugs or to a lifestyle that was disease prone, the result is still a non-caring parent. Whether in her heart she doesn't care or whether the realities are that she is unable to care, or whether the realities are that she is on too many drugs to care, or whether the realities are that she is too drunk to care, or whether the realities are that she too was so unloved that she cannot care, the outcome is the same: she doesn't care. And so you have a baby who is about to grow up in a home in which there is no love. He is lost from the start.

As a fellow at the University of Cincinnati, we looked at our statistics regarding infants of heroin addicts. We knew that by six months to one year of age, 85% of those children would no longer be in their home. We knew that 30 to 40% of them would be abused and battered. We knew that 10 to 15% of them would probably be killed. And then you can say, "Well, at least we can get them out into foster homes". Terrible solution. As you know, in most states, the child has to battered before they can be removed from the home. Neglect has to be proven. If you are lucky enough to capture the child before the battering is so great that the child dies from it or is permanently damaged from it, then you may then successfully find a home. However, frequently the sagas of foster placement heap tragedy upon tragedy. Although many foster parents are loving people, the child still doesn't have somebody who says, "I will love you unconditionally and no matter what, you will be mine forever. Some months after placement, the natural mother may petition and get the child back only to repeat the cycle and the child is placed again, perhaps in a different foster home. Perhaps the child survives to an age where he has become a behavior problem and then the foster parent can call the social worker with the message, "I am sorry, we just can't handle this child, you will have to take him to another home". And the child grows and learns that there is no such thing as unconditional love. He learns that he can be rejected at will and nobody need make a permanent commitment to him.

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Members of the Committee, you have been listening, not merely to a compilation of facts and figures, but to a scenario of the shredding of the very fabric of society. The toll on human personality is unmeasurable. The further tragedy is the multiplier effect. These children will pass on their misery to their own children and to their children's children and on and on and on. I can tell you that the even larger tragedy is that all of this may be a preventable and unnecessary waste of lives.

The final result is an expanding society of adults who have grown up without love. There is no light side for such people. Their lives are all gray or black. Our capacity to love is the enabler of joy, of achievement, of deeds and goals which contribute positively to mankind. Scriptures teach us to "train up a child in a way that he should go." They teach us "to despise not those little ones for, in Heaven, their angels behold the face of the Father" because He loves them so.

Therefore, may God bless the efforts of this committee on behalf of these little ones whose lives and futures are so important to us all. Thank you.

Chairman MILLER. Thank you.
Dr. Clarren.

STATEMENT OF DR. STERLING K. CLARREN, ASSOCIATE PROFESSOR OF PEDIATRICS, SCHOOL OF MEDICINE, UNIVERSITY OF WASHINGTON, SEATTLE, WA

Dr. CLARREN. Mr. Miller, it is a pleasure to be here today, and to talk to you and to hear the other speakers who have addressed this committee.

We have heard a lot of testimony this morning about potential epidemics in this country, and potential crises. I am here today to talk about alcohol, which is not a potential problem in this country. Fetal alcohol damage is at epidemic proportion now, yet I often wonder why it is still such a quiet problem.

Alcohol has been suspected of causing fetal damage since antiquity. But it has only been in the last 10 years that we have identified specific birth defects related to this particular drug.

Fetal alcohol syndrome is a specifically defined disorder. It is diagnosed only when all of the following deficits are present in a single patient. These deficits are pre and postnatal growth deficiency. A set of specific facial anomalies. Major malformations, especially of the heart and bones. And central nervous system dysfunction, that includes abnormal brain structure, intellectual and behavioral deficits. Brain damage is clearly the most serious consequence of this condition.

It is permanent, and cannot be ameliorated by an enriched environment, or a vigorous educational program.

Children with all of the characteristics of FAS are distinctly recognizable as damaged by alcohol. No other environmental agent, or genetic condition produces this unique cluster of anomalies.

While there is no evidence that malnutrition, cigarette smoking, or other drugs produce FAS, they may potentiate alcohol's damage. For example, neonatal growth deficiency is associated with gestational alcohol exposure, and cigarette exposure.

A child—a fetus exposed to both is often smaller than a fetus exposed to either.

Based on assessments done at other centers in five different countries in the United States, Germany, France, Spain, and Sweden, the frequency of fetal alcohol syndrome has been calculated as one to two live births per thousand.

This incident rate is considered conservative, since many infants with FAS are missed in the neonatal period, and they are only diagnosed later in childhood.

FAS incidence may increase in subcultures of the populations where alcohol use varies from the social norm. FAS incidence figures for several native American groups in the Southwest, show that that Navajo and the Pueblos have comparable FAS rates to the general rates of society—1 to 2 per 1,000. While the Plains Indian groups have a rate of approximately 1 in 100 births.

The reason for this variation is not clear. It may come from differences in consumption, or from genetic differences that affect metabolism and alcohol. It is an important question that deserves further attention.

It is important to also note that fetal alcohol syndrome is not the only adverse outcome from gestational alcohol exposure. While it is indicative of the problem, it does not reflect the total.

Experiments in animal models have confirmed that alcohol can alter the brain's anatomic structure and function, without producing any external change in the offspring.

Alcohol may also produce isolated growth deficiency, or some other cluster of birth defects. Unlike children with FAS, who are easily identified, children solely blunted in growth or intelligence by alcohol cannot, as yet, be clinically recognized.

Because there are so many factors that determine human growth and intelligence, establishing solid estimate figures of the frequency of these alcohol-related birth defects is not possible. Guestimates place the frequency at two to three times the rate of fetal alcohol syndrome, per se.

Even using the FAS incident figures alone, we find that alcohol is, without any question, the leading known environmental cause of fetal damage. Using the incident rate of 1 to 2 children per 1,000, and noting that 1 percent of the population, by definition, has an I.Q. below 70, then one has identified alcohol as being responsible for, conservatively, 10 to 20 percent of the mentally retarded persons in our society.

Scientists are currently trying to establish a dose response curve for fetal alcohol damage. Basically, this involves measuring the alcohol consumption of pregnant females, and comparing this to the extent of their children's impairment.

Unfortunately, this is anything but straightforward. People generally do not keep accurate track of the ounces of alcohol they consume, and they generally underestimate their consumption.

While it is relatively easy to identify children with FAS, subtle alcohol-related birth defects are usually found only through large longitudinal and statistically controlled studies.

Because of human physiologic variability, predicting the risk of fetal damage from alcohol consumption is complex. Women may drink the same amount of alcohol, yet absorb it differently, or metabolize it differently. Fetuses who are exposed to the same amount of alcohol may withstand alcohol exposure differently. There are reports of fraternal twinning, in which one twin is more damaged than the other.

The timing of alcohol exposure during pregnancy is critical, although there is no period in pregnancy that is immune from alcohol's harm. Each embryonic task of organization and growth has its own period of especial vulnerability. Consequently, we have little criteria at present by which to advise an individual woman as to the risk she takes in consuming alcohol during pregnancy.

While most children born to chronic alcoholics will have FAS, or isolated birth defects, some of those children will be normal. On the other hand, while most children born to light social drinkers will be normal, some may have blunted growth and development.

Because of the difficulties in determining how much alcohol a woman actually consumes, and the true extent of the fetal damage, animal models are needed to establish the bare essentials of the dose response curves.

Dose response data cannot be easily extrapolated from common laboratory animals like mice, rats, and hamsters, since they metabolize alcohol differently from humans. And much development which occurs fetally in humans occurs postnatally in these small creatures.

Furthermore, these animals lack the complex cognitive functioning that is impaired in humans exposed to moderate amounts of alcohol.

For these reasons, a nonhuman primate model is necessary to understand alcohol's teratogenicity. My colleagues and I at the University of Washington Regional Primate Center have developed a model for alcohol-related birth defects in the pigtailed macaque monkey.

In a project funded by NIAAA, we have given alcohol to pregnant animals once a week, from the beginning of gestation to the end. Our aim is to mimic Saturday night drinking, which is currently a typical pattern of drinking among women who still drink during pregnancy. We are now in the final stages of this project. All 117 pregnancies are completed. But not all the infants are yet assessed.

Within 6 months, we should have information correlating weekly exposure of alcohol and fetal abnormalities.

The question that the model will not address, but one that could be answered in later studies, is whether or not damaged produced by early gestational exposure could be reversed by later gestational abstinence.

Regardless of any project's future findings, one fact is clear. Fetal alcohol exposure is a leading cause of congenital brain damage. While this condition is basically untreatable, it is completely preventable.

Since there is no benefit to pregnant women drinking we fully agree with the Surgeon General's advice that it is safest for women to abstain from alcohol entirely during pregnancy.

There are three groups of women who will not or cannot heed this advice. Women who drink in their usual fashion because they do not know they are pregnant. Chronic alcoholics, who cannot stop drinking. And adolescents or older women, who are either denying their pregnancy, or acting out in a destructive fashion.

Data should be available over the next few years to provide counseling for women who have inadvertently exposed their fetus to some alcohol in early gestation. For the latter high risk groups, prevention of alcohol-related birth defects will only come through the kinds of interventive programs that we are discussing this morning. Thank you.

[Prepared statement of Sterling Clarren, M.D., follows:]

Prepared Statement of Sterling K. Clarren, M.D., Associate Professor of Pediatrics, School of Medicine, University of Washington, Director, Craniofacial Program, Children's Orthopedic Hospital & Medical Center, Seattle, WA WA

Alcohol has been suspected of causing fetal damage since antiquity, but scientific evidence has only verified the association of alcohol and birth defects in the last ten years. Fetal alcohol syndrome (FAS) is a specifically defined disorder that is diagnosed only when all of the following deficits are observed in a patient: 1) prenatal and postnatal growth deficiency, 2) a specific set of facial anomalies, 3) major malformations, especially of the heart and bones, and 4) central nervous system dysfunction, including abnormal brain structure, intellectual and behavioral deficits.

Brain damage is clearly the most serious consequence of this condition -- it is permanent and cannot be ameliorated by an enriched environment or a vigorous education program.

Children with all the characteristics of FAS are distinctly recognizable as damaged by alcohol; no other environmental agent or genetic condition produces this unique cluster of anomalies. While there is no evidence that malnutrition, cigarette smoking or other drugs produce FAS, they may potentiate alcohol damage. For example, neonatal growth deficiency is associated with both gestational alcohol exposure and cigarette exposure; a fetus exposed to both may be smaller than if it were exposed to either drug alone.

Based on assessments in done in urban centers in five different countries (The US, Germany, France, Spain, and Sweden), the frequency of FAS has been calculated at 1-2 live births per 1000. This incidence rate is considered conservative, since some infants are missed in the neonatal period and only recognized later in childhood.

FAS incidence may increase in subculture populations where alcohol use varies from the social norm. FAS incidence figures for several Native American groups in the Southwest show that the Navajo and Pueblo groups are comparable to overall rates, while the Plains group has a rate of 9.8 per 1000. The reason for this variation is not clear -- it may stem from differences in consumption or from genetic differences that affect metabolism of alcohol. This question deserves further attention.

It is important to note that fetal alcohol syndrome is not the only adverse outcome from gestational alcohol. While it is indicative of the problem, it does not reflect the total picture. Experiments in animal models have confirmed that alcohol can alter the brain's anatomic structure and function without producing any external change in the offspring. Consequently, alcohol may also produce isolated growth deficiency or some other cluster of birth defects. Unlike children with FAS -- who are easily identified -- children solely blunted in growth or intelligence by alcohol cannot as yet be recognized. Because there are so many factors that determine human growth and intelligence, establishing solid estimates of the frequency of these alcohol-related birth defects is not yet possible. Guestimates place the frequency at 2 to 3 times the rate of fetal alcohol syndrome per se.

Even using the FAS incidence rate alone, however, we find that alcohol is without any question the leading known environmental cause of fetal damage. Using the incidence rate of 1 to 2 children per 1000 and noting that 1% of the population has an IQ below 70, then by definition alcohol is responsible for 10 to 20 percent of the mentally retarded persons in our society.

We are currently establishing a "dose-response curve" for fetal alcohol damage. Basically, this involves measuring the alcohol consumption of pregnant females and comparing this to the extent of their children's impairment. Unfortunately, this is anything but straightforward. People generally do not keep accurate track of the ounces of alcohol they consume and they generally underestimate consumption. While it is relatively easy to identify FAS, subtle alcohol-related birth defects are usually found only through large, longitudinal and statistically controlled studies.

Because of human physiological variability, predicting the risk of fetal damage from alcohol consumption is complex. Women may drink the same amount of alcohol yet absorb or metabolize it differently. Fetuses seem to have differing levels of resistance to alcohol: there are several reports of fraternal twinning where one fetus is more damaged than the other. The timing of alcohol exposure during pregnancy is critical, and although there is no period in pregnancy that is immune from alcohol's harm, each embryonic task of organization and growth has its own periods of especial vulnerability.

Consequently, we have little criteria at present by which to advise an individual woman as to the risk she takes in consuming alcohol during pregnancy. While most children born to chronic alcoholic women will have FAS or isolated alcohol-related birth defects, some may be normal. On the other hand, while most children born to a light social drinker will be normal, some may have blunted growth and development.

Because of the difficulties in determining how much alcohol a woman actually consumes and the true extent of infant damage, animal models are needed to establish the dose-response curves. Dose-response data cannot be easily extrapolated from common laboratory animals like mice, rats and hamsters, since they metabolize alcohol differently than humans and much development which occurs fetally in humans occurs post-natally in these small creatures. Furthermore, these small animals lack the complex cognitive functioning that is impaired in humans exposed to moderate amounts of alcohol. For these reasons, a non-human primate model is necessary to understand alcohol teratogenicity in humans.

My colleagues and I at the University of Washington Regional Primate Center have developed a model for alcohol-related birth defects in the pigtailed macaque monkey. In a project funded by NIAAA, we have given alcohol to pregnant animals once a week from the beginning of gestation to the end. Our aim is to mimic Saturday night drinking, a typical pattern of drinking among women who still drink during pregnancy.

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Regardless of any project's future findings, one fact is clear: fetal alcohol exposure is a leading cause of congenital brain damage. While this condition is basically untreatable, it is completely preventable. Since there is no benefit in pregnant women drinking, we fully agree with the Surgeon General's advice that it is safest for women to abstain from alcohol entirely during pregnancy.

There are three groups of women who will not or cannot heed this advice: women who drink in their usual fashion because they do not know that they are pregnant; chronic alcoholics who cannot stop drinking; and adolescents who are either denying pregnancy or acting out in a destructive fashion. Data should be available over the the next few years to provide counseling for women who have inadvertently exposed their fetus to some alcohol in early gestation. For the latter high risk groups, prevention of alcohol-related birth defects will only come with improved general interventive programs.

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Bench and Bedside
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Recognition of Fetal Alcohol Syndrome

Sterling K. Clarren, MD

THERE has been concern since antiquity that the ingestion of alcohol by the pregnant woman could damage her unborn child. Modern scientific warnings about gestational alcoholism began with Sullivan in 1899,[1] Rouquette in 1957,[2] and Lemoine et al in 1967,[3] who all noted the increased rates of stillbirth, growth deficiency, and malformations among the offspring of alcoholic women. Alcohol teratogenesis was brought to widespread public attention by Jones et al[4] in 1973. These authors believed that alcohol could produce a specific recognizable pattern of malformation, which they termed "fetal alcohol syndrome" (FAS). Over the last eight years, maternal consumption of alcohol has become recognized through extensive human and animal studies as a major fetal health hazard—a leading known cause of mental retardation.

Table 1.—Facial Characteristics in Fetal Alcohol Syndrome*

	Features Necessary to Characteristic Face	Associated Features
Eyes	Short palpebral fissures	
Nose	Short and upturned in early childhood; hypoplastic philtrum	Flat nasal bridge; epicanthal folds
Maxilla	Flattened	
Mouth	Thinned upper vermilion	Prominent lateral palatine ridges; cleft lip with or without cleft palate; small teeth
Mandible		Retrognathia in infancy; micrognathia or relative prognathia in adolescents
Ears		Posterior rotation; abnormal concha

*Expanded from Clarren and Smith.[5]

Syndrome Recognition

Variability in phenotype occurs in most dysmorphic syndromes. By clinical appearance alone, both false-positive and false-negative cases are found in conditions that have a laboratory sine qua non, like chromosomal disorders, congenital endocrinopathies, and congenital infections. Phenotypic variability can be extreme in teratogenic conditions where the fetal outcome may be dependent on the dose, the timing and pattern of gestational exposure, the metabolism of the mother, the metabolism of the fetus, or other environmental or genetic factors. Syndrome identification is further hampered by the lack of standard methods for recognition and nomenclature for describing minor malformations.

Since any human organ or feature has only a limited number of ways that it can go awry, a single anomaly is rarely found in only one malformation syndrome. In most dysmorphic conditions without a confirming laboratory test, a cluster of anomalies is described that is as unique as possible. The apparently unique cluster of anomalies found among fetuses exposed to ethanol has been termed FAS. This pattern of malformation is described in the next section. If FAS is like most other dysmorphic conditions, occasional phenocopies of other etiologies are to be expected.

The Diagnosis of Fetal Alcohol Syndrome

The clinical features of FAS are as follows: (1) prenatal and postnatal growth deficiency, (2) CNS dysfunction, (3) a particular pattern of facial characteristics, and (4) major organ system malformations.[5]

The growth deficiency is usually moderate. Affected children are below the third percentile for height and weight. Men with FAS have been between 158 and 168 cm in height. Adipose tissue is especially reduced. No gastroenteropathies, metabolic disturbances, or hormonal aberrations have been found. Bone age is usually normal. Apparently, children with FAS are constitutionally small, and little can be done to enhance their growth.

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Fig 1.—Left, Coronal section of brain of 4-year-old with fetal alcohol syndrome showing typical lesions of microcephaly and greatly reduced white matter. Right, Example of one of numerous neuronal heterotopias found along the ventricular surface. Errors in neuronal and glial migration have been hallmark of alcohol's teratogenic effect on brain.

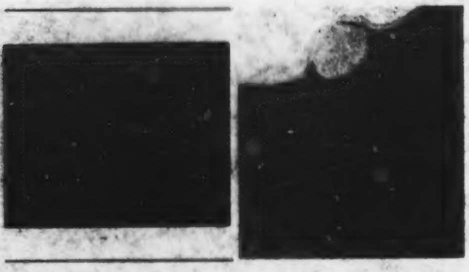

Fig 2.—Fetal alcohol syndrome in newborn, toddler, and preschooler. Even in different ages and different races, short palpebral fissures and perioral structures remain consistently anomalous. Small nose and jaw and flat midface may improve with age.

Fig 3.—Drawing by elementary schoolchild after completing curriculum in preventing birth defects. Early education may be one important method of fetal alcohol syndrome prevention.

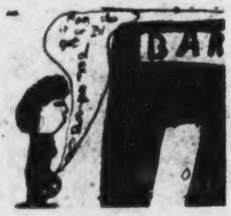

Table 2.—Malformations in Fetal Alcohol Syndrome*

- **Cardiac**
  - Atrial septal defects
  - Ventricular septal defects
  - Aberrant great vessels
  - Tetralogy of Fallot
- **CNS**
  - Malformations of neuronal and glial migration
  - Microcephaly
  - Hydrocephaly
  - Anencephaly
  - Porencephaly
  - Meningomyelocele
  - Lumbosacral lipoma
- **Cutaneous**
  - Hemangiomas
  - Hirsutism in infancy
- **Embryonal Tumors**
  - Neuroblastoma
  - Adrenal carcinoma
  - Hepatoblastoma
  - Ganglioneuroblastoma
  - Sacrococcygeal teratoma
- **Genitalia**
  - Hypospadias
  - Labial hypoplasia
- **Hepatic**
  - Extrahepatic biliary atresia
- **Muscular**
  - Hernias of diaphragm, umbilicus, or groin
  - Diastasis recti
- **Skeletal**
  - Hypoplastic nails
  - Shortened fifth digits
  - Radioulnar synostosis
  - Flexion contractures
  - Camptodactyly
  - Clinodactyly
  - Pectus excavatum and carinatum
  - Klippel-Feil syndrome
  - Hemivertebrae
  - Scoliosis
- **Renal**
  - Aplastic, dysplastic or hypoplastic kidneys
  - Horseshoe kidneys
  - Ureteral duplications
  - Megaloureter
  - Hydronephrosis
  - Cystic diverticula
  - Vesicovaginal fistula

*From Clarren and Smith.[1]

Microcephaly is usually present from birth and may be the first sign of CNS dysfunction. In autopsied cases of infants with FAS, the brains have shown similar types of malformations caused by failure or interruption in neuronal and glial migrations. The most consistent anomalies have been cerebellar hypoplasia and cerebral dysgenesis, with associated heterotopic cell clusters. While these newborns had extremely disorganized brains, survivors with FAS may have less overwhelming CNS malformation. Recently, a 4-year-old with FAS died in an accident. Based on computed axial tomograms of other survivors, her brain may be a more typical example of CNS disorganization. Her brain showed small size, marked reduction in cerebral white matter, and neuronal heterotopias along the lateral ventricular surfaces (Fig 1).

Newborns with FAS are usually irritable and tremulous. They often have apparent hyperacusis and poor suck. Infants who are intoxicated at birth metabolize ethanol extremely slowly, since they lack hepatic ethanol dehydrogenase. Seizures and other neurological problems have rarely been noted during withdrawal. Treatment is symptomatic.

Older children are generally hypotonic and have mild cerebellar dysfunction. Hypertonicity has been observed on occasion, and a diagnosis of cerebral palsy was considered in these patients. Seizures beyond the newborn period have been exceedingly rare, although EEG abnormalities are noted. Hyperactivity, especially in fine motor movement, seems to characterize the older children. Some observers have treated these children with drugs such as methylphenidate. This approach remains controversial.

The average IQ of children with FAS has been in the mildly retarded range (60 to 75). Similar intelligence scores have been found using a wide range of testing tools in centers in the United States,[9] Germany,[7] and France.[10] In at least one study, intelligence could not be improved with improved home and social environments.[11]

Since many conditions feature growth and mental deficiency, it has become the striking facial appearance of children with FAS that leads to the secure diagnosis. There are numerous facial anomalies in this disorder as listed in Table 1. A small cluster of anomalies produce the characteristic face in small children. These are short palpebral fissures, short upturned nose, hypoplastic philtrum, hypoplastic maxilla (flat midface) and thinned upper vermilion.[1] In older children and adults, variable growth of the nose and mandible may change the typical appearance somewhat (Fig 2).

In the past the shortened palpebral fissures have suggested mild growth deficiency of the eye. Frank microphthalmia has been rare. Recent evidence suggests that mild retinal aberrations are more common.[12] Strabismus and myopia are frequent eye problems, and ptosis and blepharophimosis have been reported.

When defining FAS by growth deficiency, brain dysfunction, and characteristic face, no other single malformation is found in a majority of cases. The list of anomalies that may occur at a higher-than-chance frequency continues to grow larger annually. The current list is found in Table 2.[1,13-18]

The Spectrum of Ethanol Teratogenesis

Since the recognition of FAS, it has become clear that in any specific patient each individual anomaly can vary in severity and any subcombination of anomalies can occur. When a person's cluster of anomalies is inadequate for confident syndrome identification, we suggest the term "possible fetal alcohol effects" be used in the differential diagnosis. In some patients, behavior and intelligence can be altered without associated diagnostic changes in growth, head circumference, or facial morphogenesis.

Mechanisms of Teratogenesis and Dose Response Curves

An often repeated question has been whether ethanol could be demonstrated to be the specific teratogenic agent in FAS. Could the fetal damage be due to a combination of malnutritional and environmental factors that are parts of the alcoholic's life-style? The scope of this review precludes full discussion of the extensive animal studies that have now been completed and that demonstrate the teratogenic properties of ethanol in a wide variety of species.[19] In humans FAS has not been found in nondrinking, malnourished populations. Ethanol remains the only common environmental agent consumed by women bearing children with FAS. Of course, cigarette smoking, drug ingestion, and malnutrition may have additive effects that make the fetal damage more severe.

Several problems have made the establishment of firm fetal risks at variable maternal drinking levels difficult. Alcohol consumption has been generally measured by self-reports that may be of uncertain validity. Patterns of drinking vary almost daily; it is unlikely that any two fetuses have ever been subjected to the exact same exposure pattern. It has been difficult to identify the more mildly affected persons. Still, important correlations have been found.

The likelihood of miscarriage does seem to increase directly with consumption. The risk of abortion is twice as high in women drinking 1 oz of absolute alcohol as infrequently as twice per week. This may be a fetotoxic rather than teratogenic effect.[20]

Infant size inversely varies with alcohol use. Consumption of 1.6 oz of absolute alcohol per day produces infants averaging 59 g less than controls.[21]

Fetal alcohol syndrome occurs in 30% to 45% of infants born to chronic, heavy daily drinkers.[4,22] Binge drinking and moderate drinking, especially in the first trimester, carry a lower but an unknown risk. No upper level of consumption has been established that allows for prediction of definite damage to the fetus nor a lower level that excludes the possibility of fetal harm.

Majewski et al[9] have suggested that chronicity of alcoholism increases the likelihood of FAS. We have estimated that in our clinic 75% of women bearing FAS infants are dead within five years of the affected child's birth. Could alcoholic liver damage alter the metabolic pathways of ethanol or prolong its degradation so that the teratogenic effects are enhanced? Acetaldehyde, a major metabolite of ethanol, has been shown to be itself teratogenic.[23,24] Variations in ethanol metabolism and its relationship to teratogenesis is an area of research that deserves active investigation.

Incidence and Prevalence

Fetal alcohol syndrome has been reported to occur in between one in 600 and one in 1,000 live births in the United States,[25] France,[26] and Sweden.[27] In each study this was only the incidence of clear cases of FAS in principally middle-class populations. Frequency has not yet been reported in heavily drinking ethnic or racial groups. These figures, which underreport the full scope of teratogenesis from alcohol, already establish FAS as a leading known cause of mental retardation.

Prevention

Clearly, the incidence of FAS will vary with alcohol consumption. Some authorities have asserted that pregnant alcoholics be advised to abort their conceptions. We believe that the data remain too incomplete for such advice. In our clinics we inform pregnant alcoholic users of the potential hazards of continued intake and strongly advise discontinuation of alcohol from that point. Therapeutic abortion is often discussed as an option, but is not actively recommended.

The notion of mothering from conception, not birth, must be fostered in the nonpregnant. Few parents would give an infant an ounce of liquor; they should understand that gestational drinking is the same thing or worse. Early education programs may be an important aspect of prevention. In the Seattle area, an FAS curriculum is being introduced into the primary grades. It has been well received and is available to other school districts[28] (Fig 3). Identification of female alcoholics before pregnancy is also important. The National Institute of Alcoholism and Alcohol Abuse has funded two programs to detect high-risk women and provide referral service for treatment (grants No. NIAAA 1H84 AA03736-01, NIAAA 1H84 AA03922-01).

This study was supported in part by a grant from the Birth Defects Foundation-March of Dimes Medical Service.

David W. Smith, MD, died on Jan 23, 1981. It was largely through his efforts that FAS was brought to international public attention. His insights and enthusiasm stimulated many others to pursue research that has amplified understanding of this important fetal health hazard. His work in FAS was only one of his many major contributions to improving the health of children. His death is a great loss for all who knew him and the medical community.

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Chairman MILLER. Thank you.
Dr. Marks.

STATEMENT OF DR. JAMES S. MARKS, ASSISTANT DIRECTOR FOR SCIENCE, CENTER FOR HEALTH PROMOTION AND EDUCATION, CENTERS FOR DISEASE CONTROL, ATLANTA, GA

Dr. MARKS. Thank you. I am going to talk a little bit about the issues of smoking during pregnancy, an addiction that is not generally considered in the same light as the addictions we have heard about earlier.

In the nearly three decades since cigarette smoking was first shown to be associated with lower birthweight among infants born to smoking women, a large number of studies have confirmed and extended these findings. The 1980 Surgeon General's report, entitled "The Health Consequences of Smoking for Women," highlighted some of those findings.

Cigarette smoking during pregnancy is clearly associated with reduction in infant birthweight. The reduction averages up to 200 grams for full-term newborns. The magnitude of a birthweight deficit increases as the number of cigarettes smoked by the mother per day increases. Further, on average, a woman who smokes has at least twice the risk of having a low birthweight infant than does a similar woman who does not smoke cigarettes.

In five large studies carried out in the United States and Canada, between 21 and 39 percent of all low birthweight is attributable to maternal cigarette smoking. The major cause appears to be a direct effect of smoking on fetal growth, most likely operating through the effects of nicotine, and its metabolites, on fetal growth or through reduced oxygen availability from carbon monoxide in the cigarette smoke that reduces the oxygen carrying capacity within the blood.

In addition to this direct effect on birthweight, other important relationships have been found between the maternal smoking and increased likelihood of stillbirths; increased risk of premature delivery and increased risk of sudden infant death syndrome. In addition, studies more and more are showing that there is an increased likelihood of behavioral and learning problems for the infant.

Dr. Clarren has indicated the fact that these effects may be multiplicative with alcohol. And many of the women who smoke cigarettes also drink alcohol, and vice versa. In fact, your witness this morning, Jenny, actually did not mention the fact that she smoked cigarettes fairly extensively during her last two pregnancies, though not in the first two.

Because of the consistency of the harmful effect of smoking on fetal growth, several of us at the Centers for Disease Control proposed in a recent article that the term "Fetal Tobacco Syndrome" be used to identify those children whose growth retardation was probably due to the fact that their mother smoked during pregnancy.

Given this background, how important is the problem of smoking during pregnancy in the United States today?

As more has been learned about causes of low birthweight and infant mortality, it has become increasingly clear that in terms of the proportion of low birthweight infants due to known factors, cigarette smoking is the single, most important known determinant of poor fetal growth in the United States.

Currently, about 29 percent of all adult U.S. women smoke. This rate has remained distressingly stable over the last two decades, in contrast to the very dramatic decline that has occurred among male smokers. Only about 10 to 15 percent of all women smokers quit smoking when they become pregnant. The figures may be worse for low-income women.

Preliminary analyses from the Centers for Disease Control nutrition surveillance system suggest that currently only about 6 to 7 percent of pregnant women smokers in WIC clinics quit during their pregnancy. Usually these quitters are the lightest smokers.

As estimated from the national natality survey of the National Center for Health Statistics, about 25 percent of all pregnant women in the United States smoke throughout their pregnancy. Since there are 3.6 million births in the United States per year, approximately 900,000 infants are born yearly in the United States exposed to the effects of tobacco in utero. Disturbingly, the rates of smoking are highest among those women who are at greatest risk of poor pregnancy outcome for other reasons. That is, the less well educated, teens, unmarried women, those who also consume alcohol and those with lower income.

A powerful illustration comes from the State of Missouri, which collects good information on smoking during pregnancy from its birth certificates. In Missouri, in recent years, over 45 percent of women receiving prenatal care in public clinics and a similar percentage of women in the WIC Program smoke cigarettes—rates much higer than the 25 percent of pregnant women in general. Even taking into account, though, the high risk of low birthweight and the high risk of infant mortality for infants of those women, the evidence is that the cigarettes that these women smoke further increase their risk of having a low birthweight baby or one of the other pregnancy complications mentioned earlier.

The next question from a public health perspective is, is there something we can do about this situation? In a 1983 study of several hundred women carried out by Dr. Mary Sexton and colleagues at the University of Maryland, the rate of smoking cessation was twice as high among a group of women given specific counseling and support to stop smoking during pregnancy. That is, among those given the counseling and support, 43 percent stopped smoking during pregnancy. This intervention led to an average increase of over 100 grams in mean birthweight of the newborn infants of the women in treatment groups.

In a second study recently published by Dr. Richard Windsor and colleagues, from Birmingham, AL, several hundred women attending three clinics were enrolled in a self-help program, where they were given a very short counseling session, and then a self-help guide to quit smoking. Again, the rate of cessation was nearly twice as high in the treatment group as in the uncounseled control group.

Thus, it appears that we are learning how to increase substantially the number of women who can stop smoking during pregnancy. However, it is equally clear that the overwhelming majority of pregnant women in the United States receive no formal help to stop smoking.

We, at the Centers for Disease Control, will soon be working with a State health department to develop and evaluate methods for incorporating formal smoking cessation efforts into public prenatal and WIC clinics. It is our intention that this demonstration project provide us with the information and experience needed to assist other States to incorporate the methods that have been developed through the previously mentioned research into their programs, so that they can reach large numbers of women of great need.

Although much remains that is unknown about the prevention of low birth weight and infant mortality, it is critically important that effective means of prevention of low birthweight, when they are known, be fully incorporated into existing prenatal care. Smoking cessation efforts are inexpensive, when compared to the expenditures for low birthweight infants, requiring intensive care. The expenses were estimated to be about $8,000 per infant, in 1978 dollars, in an Office of Technology assessment study. Recently, I see, in your facts that you have provided here, that it is at $24,000 per infant in this hospital.

Based on existing evidence, there is a great likelihood that smoking cessation intervention programs will be highly cost effective.

Let me assure you, though, that the substantial opportunity that this represents for improvement in the low birthweight rate in the United States will not be easy to seize. It is difficult to get the women who smoke the most heavily to quit during pregnancy. It is also clear that the women attending public clinics are more likely to delay beginning their prenatal care, and that those who begin prenatal care late are least likely to quit smoking.

The rate of low birthweight in the United States currently stands at 6.8 percent of all live births. The available evidence indicates that if we could eliminate smoking among pregnant women, we estimate that the rate of low birthweight infants born in the United States would decrease to approximately 5 percent of all births, a greater decrease than has occurred in the past 35 years in this country.

Before I finish my testimony, I would like to mention one other thing.

Earlier, we heard discussion about the issue of education, and its effects. There is education that is effective for promoting healthy behaviors for women who are currently or about to become pregnant. And we also know that school health education has been shown to be effective, at least in delaying the initiation of smoking among children in grades 4 through 6.

That is, in a large study of 30,000 children, 40 percent fewer children initiated smoking in the seventh grade if they had been exposed to school health education than those not so exposed.

Thank you for your attention.

[Prepared statement of James Marks, M.D., follows:]

PREPARED STATEMENT OF JAMES S. MARKS, M.D., ASSISTANT DIRECTOR FOR SCIENCE, CENTER FOR HEALTH PROMOTION AND EDUCATION, CENTERS FOR DISEASE CONTROL, PUBLIC HEALTH SERVICE, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Good morning Mr. Chairman and members of the Committee.

I am Dr. James Marks, Assistant Director for Science, Center for Health Promotion and Education, Centers for Disease Control (CDC). I am especially pleased this morning to be able to discuss with you the issue of cigarette smoking during pregnancy.

In the nearly three decades since cigarette smoking was first shown to be associated with lower birthweight among infants born to smoking women, a large number of studies have confirmed and extended these findings. The 1980 Surgeon General's Report, entitled Health Consequences of Smoking For Women, highlighted some of those findings.

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In five large studies carried out in the United States and Canada, between 21 and 39 percent of all low birthweight was attributable to maternal cigarette smoking. The major cause appears to be a direct effect of smoking on fetal growth, most likely operating either through effects of nicotine and its metabolites on fetal growth or through reduced oxygen availability due to the effect of carbon monoxide on the oxygen carrying capacity of the blood of the mother. In addition to this direct effect on birthweight, other important relationships have been found between maternal smoking and:

1. Increased likelihood of stillbirths;
2. Increased risk of premature delivery and premature rupture of the mother's membranes;
3. Increased risk of sudden infant death syndrome;
4. Increased likelihood of premature separation of the placenta from the uterine wall; and
5. Increased likelihood of behavioral and learning problems for the infant.

Because of the consistency of the harmful effect of smoking on fetal growth, several of us at the Centers of Disease Control proposed in a recent article that the term 'Fetal Tobacco Syndrome' be used to identify those children whose growth retardation was probably due to the fact that their mothers smoked during pregnancy.

Given this background, how important is the problem of smoking during pregnancy in the U.S. today?

As more has been learned about causes of low birthweight and of infant mortality, it has become increasingly clear that in terms of the proportion of low birthweight infants due to known factors, cigarette smoking is the single, most important determinant of poor fetal growth in the United States.

Currently about 29 percent of all adult U.S. women smoke. This rate has remained distressingly stable over the last two decades in contrast to the very dramatic decline that has occurred among male smokers. Only about 10 to 15 percent of women smokers quit smoking when they become pregnant. The figures may be worse for low income women. Preliminary analyses from CDC's Nutrition Surveillance System suggest that currently only 6 to 7 percent of pregnant women in WIC clinics (Special Supplemental Food Program for Women, Infants and Children) quit during their pregnancy. Usually these quitters are the lightest smokers. As estimated from the National Natality Survey of the Department's National Center for Health Statistics, about 25 percent of all pregnant women in the U.S. smoke and continue to smoke throughout their pregnancy. Since there are 3.6 million births in the United States per year, approximately 900,000 infants born yearly in the U.S. are exposed to the effects of tobacco in utero. Disturbingly, the rates of smoking are highest among those women who are at greatest risk of poor pregnancy outcome for other reasons--the less well educated, teens, unmarried women, those who also consume alcohol and those with lower income.

I will now summarize some of the recent findings from the field. A powerful illustration comes from the State of Missouri, which collects good information on smoking during pregnancy from its birth certificates.

In Missouri in recent years, over 45 percent of women receiving prenatal care in public clinics and over 45 percent of pregnant women in the WIC program smoke cigarettes--rates much higher than for pregnant women in general. Even taking into account the high risk of low birthweight and the high risk of infant mortality for infants of women in public programs, the evidence is that the cigarettes that these women smoke further increase their risk of having a low birthweight baby or one of the other pregnancy complications mentioned earlier.

The next question is whether, from a public health perspective, something can be done about this situation?

In a 1983 study of several hundred women, carried out by Dr. Mary Sexton and colleagues at the University of Maryland, the rate of smoking cessation was twice as high among a group of women given specific counseling and support to stop smoking during pregnancy. That is, among the untreated control group, 20 percent stopped smoking, whereas among those given the counseling and support, 43 percent stopped smoking during pregnancy. This intervention led to an average increase of over 100 grams in mean birthweight of the newborn infants of the women in treatment groups versus control groups.
In a second study conducted by Dr. Richard Windsor and colleagues from Birmingham, Alabama, several hundred women attending three clinics were enrolled in a self-help program where they were given a short counseling session and then a self-help guide to quit smoking. Although many of these women began pronatal care later than those in the Maryland study, again the rate of cessation was nearly twice as high in the treatment group as in the uncounseled control group. Thus, it appears we are learning how to increase substantially the number of women who stop smoking during pregnancy. However, it is equally clear that the overwhelming majority of pregnant women in the U.S. receive no formal help to stop smoking.

We, at the Centers for Disease Control, will soon be working with a State health department to develop and evaluate methods for incorporating formal smoking cessation efforts into public prenatal and WIC clinics. It is our intention that this demonstration project provide us with the information and experience needed to assist other States to incorporate these methods into their programs.

Although much remains that is unknown about the prevention of low birthweight and infant mortality, it is critically important that effective means of prevention of low birthweight, when they are known, be fully incorporated into existing prenatal care. Smoking cessation efforts are inexpensive when compared to the expenditures for low birthweight neonates requiring intensive care, which were estimated to be about $8,000 per infant in 1978 dollars in a recent Office of Technology Assessment study. Based on existing evidence, there is a great likelihood that smoking cessation intervention in prenatal programs will be highly cost effective.

Let me assure you that the substantial opportunity that this represents for improvement in the low birthweight rate in the U.S. will not be easy to seize. It is difficult to get the women who smoke most heavily to quit during pregnancy. It is also clear that women attending public clinics are more likely to delay beginning their prenatal care and that those who begin prenatal care late are least likely to quit smoking.

The rate of low birthweight in the U.S. currently stands at about 6.8 percent of all live births. The available evidence indicates that if we could eliminate smoking among pregnant women, we estimate that the rate of low birthweight infants born in the United States would decrease to approximately 5 percent of all births, a greater decrease than has occurred in the last 35 years.

Thank you for your attention. I am pleased to answer any questions you might have.

Chairman Miller. Thank you very much.
Ms. Arkin.

STATEMENT OF ELAINE B. ARKIN, CHAIR, STEERING COMMITTEE, HEALTHY MOTHERS, HEALTHY BABIES COALITION, WASHINGTON, DC

Ms. Arkin. Thank you. I wanted to tell you about some of the educational activities that we can undertake to take care of some of this problem that we have been hearing about all morning.

We have been hearing about the importance of prevention and education, and the Healthy Mothers, Healthy Babies Coalition is devoted to exactly that. So, there is something going on.

The coalition is a cooperative venture of 80 national organizations including voluntary, health professional, and governmental, and they include three Federal agencies—Agriculture, Health and Human Services, and Transportation.

We all got together in 1981 with a common concern about infant mortality, and an emphasis on prevention. And a concentration on what a woman can do, herself, to help assure that she can have a healthy baby. Our focus is on education of women, their families, and the health care providers. And all of our messages are positive and they all concern prevention actions, including proper nutrition, avoidance of alcohol, tobacco, and drugs during pregnancy, and especially the importance of early and regular prenatal care. And I say especially, because you have heard that that is a problem with low-income women. And low-income women are a special audience for this coalition.

So, because of that, one of the first things we did as a group was conduct market research. We talked to as many low-income women as we could afford to do in an organized fashion. And they told us that health care is not a priority for them. Pregnancy is not considered a medical condition. They do not consider it a problem. They consider it a natural process.

So that medical attention is not something that they see is necessary, unless they have an acute symptom. And while they told us that they understood the effect of alcohol, smoking, and drugs on their own body, they did not seem to be able to make the connection between their own behavior and the health of their baby.

In fact, for these women, every day brought a new series of very real problems to overcome. And more emotional stresses. And they told us that smoking, and drinking, and use of drugs is one way that they could deal with their problems. The birth of their baby was something that was going to happen at some time in the future. It did not seem very real to them. But those everyday concerns were very real, and they needed the assistance of the emotional crutches to get them through the day.

So, using that market research, we designed an educational intervention, dealing with emotional appeals, and motivation, and using some cultural sensitivity in dealing with low-income women. We came up with a series of six very simple information cards on each of these topics, including smoking, drinking, and drug use. They are very simple. Just a little bit of information. And there is a series of posters that went with them.

And we distributed them as a subscription series, over a period of several years. So that a woman, every time she came to a clinic, could take another one home to put up on her refrigerator.

We distributed over 7 million of those cards in English and Spanish, over the past few years, never in quanitites of more than 50 at a time. They were offered through clinics and other sites serving low-income women. So, I think you can see there is a real need—a real demand for these materials, since we made them continually come back to us for additional quantities.

Now, at the same time we talked to low-income women, we talked to those health care providers who specialize in serving this audience. And they told us, as you have heard already this morning, that they were not trained to identify substance use problems in women. And much less are they able to counsel those women on how to quit, or even refer them to treatment sources.

Nor, did—they told us—did they have the time to deal with what they considered nonmedical issues, like substance use during pregnancy. So, we formed a substance abuse subcommittee of our coalition to address these health care professionals. And we designed a kit of materials for these busy professionals, including the latest scientific information, and the policy statements of their own professional associations, in order to convince them that they need to take an action. We are giving them counseling guides, to try to help them learn on their own how to counsel these women, or at least to refer them in the community for more help. We are also giving them informational materials to make their job easier, because we recognize that they have very little time in clinics to deal with these women.

Last summer, as a continuation of this investigation of what we can do to help health care providers, we asked them what they had found to be successful in their own practice in motivating low-income women to come in and stay in the system—because it is very hard to keep them there, once we get them there—1,500 of them took the time to write to us, and give us their best advice for their peers about what seemed to work—what seemed to be effective.

And while there is a long list of suggestions, the top three included the importance of coordinating all the community services that deal with these low-income women so that, together, they can form a stronger, or more compelling, group of people trying to keep women in the system.

Second, they told us that it was important to use these women themselves either as auxiliary staff or as volunteers to help educate women like themselves. And not only to perform the education, but to help them plan the appropriate kinds of intervention activities for those women.

Now, they also told us that there were a lot of things that they needed. And in the educational area, for instance, they told us that these low-income women really need parenting skills. They need a lot more materials on drug use during pregnancy. It is something that there are not very many of available right now. And they especially needed help in dealing with women's partners, because it is that sort of social support that a woman needs to stay off hazardous subetances during pregnancy.

Now, that study is going to be published as a compendium of program ideas for the health care provider—things that you can do, within your own budget, within your own clinic. And it is a book that the coalition will be looking for private and public support to distribute it as far as we can around this country. This summer it will be released.

The coalition works on three levels. We work on the national level, with our member organizations, in order to coordinate the programs that we all have to educate women and health care providers, and to try to extend those limited resources we have as far as we can. And also, to identify the gaps in programming, and the need for materials about drug abuse is certainly one of those gaps that we have identified. And then try to get one of our members to fill that gap.

On the State and local level, we work with our affiliate coalitions. And in California, in addition to the State coalition, I think there are about 15 in different communities. And we work with them, again, to find out what their needs are, so we can try to address those. And also to provide technical assistance and educational materials to them.

For example, we have just completed a project, whereby we provided a large quantity of educational materials and media materials—television and radio PSA—to 10 State coalitions to conduct a statewide, yearlong campaign to teach women about what they can do to take care of their baby during a pregnancy.

We also try to help States exchange information about successful strategies and techniques that they have found. It is difficult to measure the effects of an educational program. But some of the States that we are working with have reported back to us an improvement in their infant mortality and low birthweight rates since the implementation of these programs. They emphasize public education, improvement of communication with health care providers, and especially community participation.

So, we feel, at the coalition, that there are two things that we need now. We need a broader base of support, outside of the public health community. I think we are all converted here, and we need to bring in other kinds of people in this society to work with us, to raise this issue to a higher level on the National, State, and local agendas.

We also need to deal with these women before they become pregnant. Clearly, if we are identifying substance abuse during pregnancy, we are identifying it at a time when the very fact that the woman is pregnant makes intervention much more difficult for her.

I want to tell you one more thing, and that that is that there is a new opportunity to address those needs. A new partnership, called the National Partnership To Prevent Alcohol and Drug Abuse Among Youth. It is new. I am affiliated with it, and it includes not just the public health community, but all sectors of society—business, media, juvenile court system, parents, schools, and at all levels—State, local, and National—to try to prevent substance abuse among youth, addressing this as a community concern. Something that affects every one of us, and not just parents, and not just their children.

So, the opportunity is there, now, to increase our success by making this a priority among more groups.

But I guess whether or not it succeeds will depend on the determination and the commitment that we all give this kind of prevention effort. Thank you.

[Prepared statement of Elaine Arkin follows:]

PREPARED STATEMENT OF ELAINE BRATIC ARKIN, CHAIR, HEALTHY MOTHERS, HEALTHY BABIES STEERING COMMITTEE ON PREVENTION OF SUBSTANCE ABUSE THROUGH PUBLIC EDUCATION, CHILDREN'S HOSPITAL, WASHINGTON, DC

I am Elaine Bratic Arkin, Senior Vice President for Communications of The National Partnership to Prevent Drug and Alcohol Abuse Among Youth. I formerly served as Deputy Director of Public Affairs, United States Public Health Service, where I spent 15 years in health communications. I currently serve as volunteer chair of the Steering Committee for the Healthy Mothers, Healthy Babies Coalition, about which I will speak today.

The Healthy Mothers, Healthy Babies Coalition is a cooperative venture of 80 national voluntary, health professional, and governmental organizations including the American College of Obstetricians and Gynecologists, the American Nurses Association, the American Red Cross, the Salvation Army, the March of Dimes, and the Departments of Transportation, Agriculture, and Health and Human Services. It started in 1981 with a concern about the U.S. infant mortality rate, when representatives of these organizations met to discuss how to prevent infant morbidity and mortality through improved education of women, their families, and health care providers. Healthy Mothers, Healthy Babies messages and materials encourage preventive actions -- proper nutrition, breastfeeding, avoiding cigarettes, alcohol and drugs, and the importance of early and regular prenatal care -- actions that a woman can take to help assure that she will have a healthy baby.

Healthy Mothers, Healthy Babies prevention activities are directed at three audiences: low income women; their health care providers; and the general public.

In a 1985 report, Preventing Low Birthweight, The Institute of Medicine noted that "factors typical of socioeconomic disadvantage are linked to increased infant mortality through both higher low birthweight rates and a birthweight-independent risk of post-neonatal death".[1] C. Arden Miller, M.D., professor of Maternal and Child Health at the University of North Carolina, Chapel Hill, has reported that, "By far the most impressive correlation (of any risk factor with low birthweight) is with poverty and minority status".[2]

Coalition-sponsored market research with low income women indicated that for low income women, preventive health care is not a priority. Pregnancy is not considered a health problem requiring medical attention, but rather a natural process. Often women in the target audience only seek any kind of health treatment when physical symptoms are acute.[3]

Although the women interviewed did seem to understand the effect of smoking, drinking and drug use on their own bodies, they did not link their behavior with the health of their baby. In fact, for these women, each day brought new problems to overcome and new emotional stresses for which, they said, smoking, alcohol, and drugs offered some relief. Priorities of obtaining food and shelter and caring for their families override the importance of seeking prenatal care.[4]

The target audience has a predominantly day-to-day orientation; the birth of a baby seemed to be an intangible event, far in the future. Also, assimilation of health information often requires women to change long-standing habits and practices; these modifications may be neither understood nor supported by family and peers.[5]

Using the findings of the Juarez study to guide program direction, the Healthy Mothers, Healthy Babies Coalition developed a public education campaign incorporating emphasis on motivational appeals, cultural sensitivity, and bilingual materials written at a level appropriate to reader language skill and education.

The Coalition designed a series of six simple informational cards and matching posters on prenatal care, to be distributed through public health clinics and other sites, such as WIC offices serving low income women. Three of the messages related to substance abuse. The series was designed to produce a positive response to a very positive message: you can help assure that your baby will be healthy.

The materials were carefully pretested in inner-city and rural sites before the series was produced. The cards and posters were produced with the help and support of both public and private organizations. A total of 7 million cards, including English and Spanish versions, have been distributed across the country through targeted mail and in response to requests and reorders.

The Juarez study also interviewed health care providers serving low income women, who said that they were not trained to identify substance abuse problems in their patients, much less how to counsel them to stop. Nor did they have time to deal with these "non-medical" issues.[6]

For health care providers, the Coalition Subcommittee on Substance Use During Pregnancy has prepared a kit including the results of the latest scientific research, and the policy statements of their professional associations concerning substance use during pregnancy to convince them that action is needed. Also included will be guides to help them counsel their patients, and educational materials to make their job easier.

Last summer the Coalition asked health care providers to give us their best advice about how to motivate low income women to enter and stay in the health care system. The 1500 survey respondents told us that most important was to work with all community agencies to coordinate support services and reinforce each other in their efforts to keep women in the system. Also, they stressed the value of using community women, as volunteers or auxiliary staff, to not only educate, but also to plan appropriate activities for other women like themselves. They also told us that they needed educational materials for teens, for partners of pregnant women, and materials on drug use during pregnancy. The results of this study will be published and widely circulated this summer as a compendium of program ideas for clinics and other sites serving low income women.[7] The compendium is the first of its kind in the nation, and the Coalition will again seek to combine public and private support to make it available to providers throughout the U.S.

The Coalition works on three levels. On the national level, it coordinates the programs of its national member organizations (a list is attached), working to expand the availability of existing resources and identify gaps in education and programs; on the state and local levels it works through its affiliate chapters to assess their needs, provide technical assistance and educational materials, and an exchange of successful strategies between states. Though it is difficult to measure the effect of public education, several states report improvement in their infant mortality and low birthweight rates since the implementation of programs emphasizing public education, improved communication between providers regarding care and follow-up, and community participation by individuals and businesses.

For the general public, the Coalition has provided materials and technical support to help 10 of the 45 State Coalitions implement a year-long mass media campaign directed at pregnant women and their families. The campaign, "Take Care of Your Baby Right from the Start," also includes outreach to fathers. Other Coalition activities are highlighted in the attached summary of our 1985 annual report.

The Coalition is staffed by an Executive Secretariat which is funded by a small grant from the Public Health Service. Members contribute resources of professional and support staff time, printing, production and postage, and office space and supplies.

What is needed now for prevention of low birthweight and infant mortality is a broader base of support, beyond the traditional public health community, to include business and other segments of the private sector, raising the importance of healthy mothers, healthy babies on the national agenda. Second, the problem of substance abuse needs to be addressed before a girl or woman becomes pregnant, and the stress of pregnancy makes treatment more difficult.

There is a new national partnership now being formed; The National Partnership to Prevent Drug and Alcohol Abuse Among Youth (information attached). This partnership includes all sectors of our society - business, media, school, church, parents, volunteers, juvenile justice and health - working together at the community, state, and national levels to prevent substance abuse among young people.

The opportunity to increase our prevention efforts is there: success will depend upon the determination and commitment given to this new prevention effort.

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3. Juarez and Associates, Inc. *"Healthy Mothers" Market Research: How to Reach Black and Mexican American Women*, contract number 282-81-0082, U.S. Department of Health and Human Services, September 14, 1982, p. 99.

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5. *ibid*, p. 100.

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7. *Healthy Mothers, Healthy Babies: A Compendium of Program Ideas for Serving Low-Income Women*. (available from Healthy Mothers, Healthy Babies, Summer 1986, 600 Maryland Avenue, S.W., Suite 300E, Washington, D.C. 20024-2588).

SUMMARY OF THE
1985 ANNUAL REPORT
HEALTHY MOTHERS, HEALTHY BABIES COALITION

The HMHB Coalition experienced rapid growth and development during its third year. The Coalition added twenty new members to now include more than eighty national organizations. An Office of the Executive Secretariat was established to provide a single coordinating point for all National Coalition functions. New subcommittees on adolescent pregnancy, oral health, genetics, and injury prevention formed in response to member interests and began assembling a variety of resources to promote maternal and child health. New and revised Coalition materials were developed on a variety of topics, including how to build a local coalition and how to reach low income women.

The organizational and educational activities in state HMHB Coalitions increased in parallel with the national efforts, sparked by a successful HMHB national conference, the first of seven regional conferences, and technical assistance and program support provided by the national Coalition and its member organizations. Below are the highlights of 1985:

Public Education and Visibility for Maternal and Child Health Issues:

- The third national conference of the HMHB Coalition was held in Rockville, MD in September. Its twenty-one workshops ranging from key issues in infant mortality to resource development attracted over three hundred national, state, and local coalition participants.
- The second annual HMHB National Achievement Awards Program, conducted in conjunction with Child Health Day ceremonies in Washington, DC recognized innovation and commitment in programs from Holland, MI; Lincoln, NB; and the states of TN, CT, and SC.
- Two public service announcements (PSA), one on teen parenting, and one on nutrition during pregnancy, were developed for member use. In the first, the Reverend Jesse Jackson talks to teens about what being a man really means--taking responsibility for one's acts, "not making babies before you are ready to be a father". In the second, a couple talks about preparing for pregnancy, and the importance of good eating habits. Coalition members were also provided access to a new PSA developed by the American College of Obstetricians and Gynecologists on unintended pregnancies.
- "Take Care of Your Baby Right from the Start". Ten states participated in a mass media project with resources provided by the national HMHB Coalition and the US Public Health Service, in cooperation with the NY State Department of Health. Television, radio, and print materials in English and Spanish were offered to HMHB Coalitions who could demonstrate that their coalition was broad-based and sufficiently well organized to conduct a mass media public education campaign. The states included: FL, CA, MD, DC, TN, WI, CT, SC, NJ, KS.
- A 1986 calendar of maternal and infant health observances was compiled for national, state, and local coalition members.

- New coalition subcommittees on Adolescent Pregnancy, Oral Health, Genetics, and Injury Prevention were formed to join the already active Breastfeeding, Low Income, Substance Use, and Policy Subcommittees.

- Outreach was conducted to several thousand health care providers through HMHB exhibits at coalition members' annual national meetings.

Resource Development and Sharing:

- The first of a series of regional HMHB conferences was hosted by Maryland, with Mid-Atlantic Region representatives from DE, PA, DC, VA and WV.

- The HMHB Directory of Educational Materials, a collection of printed audiovisual materials available from government, professional and voluntary organizations, was revised for a third edition.

- The Community Connection, a HMHB primer on coalition building, was updated and expanded.

- The over 1500 survey responses to the HMHB call for strategies to reach low-income women were compiled and analyzed for the Compendium of Ideas for Reaching Low-Income Women.

- Three meetings of the national HMHB Steering Committee were held.

- Four issues of the HMHB newsletter were published and distributed to coalition members and "friends".

In the area of administration, the Office of the Executive Secretariat was established through a grant from the Public Health Service. Space was donated for the office by the American College of Obstetricians and Gynecologists.

DIRECTIONS FOR 1986

Major emphasis will be placed on state coalition building in 1986. At present, over forty states have formed Healthy Mothers, Healthy Babies coalitions, for activities ranging from public education campaigns to development of legislative strategies on maternal and child health issues.

Six regional conferences will play an important role in state coalition growth. As a supplement to the regional meetings (and in lieu of a national conference), the national Coalition will conduct a special training session for state contacts. The State Coordinators' Conference will facilitate skill-building and exchange of ideas, experiences and resources among the leaders of the state Coalitions.

Initiatives for national Coalition building will continue with expansion of the national Coalition leadership base, development of new public education resources, and continuation of the Coalition's technical assistance and national awards programs. The Coalition relies on the expertise and resources volunteered by its members.

The complete annual report is available upon request from The Office of the Executive Secretariat, Healthy Mothers, Healthy Babies, 600 Maryland Ave.,SW Suite 300 E, Washington, DC 20024, (202) 638-5577.

National Partnership
to Prevent Drug and Alcohol Abuse Among Youth
1110 Vermont Avenue, NW, Suite 428
Washington, D.C. 20005
Telephone 202/429-2940

WHY IS THERE A NATIONAL PARTNERSHIP?

Drugs and alcohol have a devastating effect on the lives and health of young people, on society and on the economy. The use of drugs and alcohol has grown to such alarming proportions that, despite many state and community prevention efforts, control presents an enormous challenge. The time has come for a major new initiative. The National Partnership brings together major forces -- including business, voluntary, professional, governmental and media -- working together to create powerful new strategies to end drug and alcohol abuse among America's youth.

WHAT CAN THE NATIONAL PARTNERSHIP DO FOR MY COMMUNITY?

The Partnership is available to help communities expand their current drug and alcohol abuse prevention activities, focus attention on what can be done to stop drug and alcohol abuse, and begin new programs. Resource lists, guidebooks, and sources of technical assistance are available to guide the assessment of community needs, organize a Partnership, identify prevention programs and resources, and work with the media.

WHAT IS THE NATIONAL PARTNERSHIP?

The National Partnership is a nationwide alliance of diverse local, regional and national organizations, united by their common commitment to prevent drug and alcohol abuse among youth. Membership is open to parent and youth groups, civic and fraternal bodies, educational and religious institutions, business and professional firms, governmental agencies, professional and other concerned organizations.

The Partnership does not provide direct services to youth; nor does it compete with other organizations for funds or clients. Rather, its energy is focused on support and aid to others so that they can work in a common cause. The Partnership exists, independent of any single point of view, to provide and support national state and community leadership to prevent drug and alcohol abuse among youth.

WHAT IS THE ROLE OF THE PARTNERSHIP?

The Partnership brings its members together to share information, identify resources, inventory prevention programs, and seek out gaps in our nationwide efforts to end alcohol and drug abuse among youth. It opens lines of communication between groups with differing interests and points of view; it taps the skills, resources and enthusiasm of individuals and organizations committed to finding new ways to work together.

HOW DOES THE PARTNERSHIP WORK?

At the national level, the Partnership coordinates exchange of information, programs, and new ideas among its members, state and local partnerships, Federal agencies, associations and societies, business and commerce, and elected and appointed officials at all levels. All member organizations are invited to serve on a Coordinating Committee which directs Partnership efforts to identify effective prevention programs ready for adoption, to build community, state , and local Partnerships, and to increase national awareness of prevention strategies available to fight drug and alcohol abuse among youth. Between quarterly Coordinating Committee meetings, information is shared through a monthly newsletter and other communications.

Through other National Partnership committees (e.g., philanthropic, programs, media and intergovernmental), members work with Partnership staff to develop strategies and materials, and provide technical assistance to communities.

At the state and local levels, the Partnership works with leaders to help communities identify their own problems and needs in order to raise abuse prevention to a community-wide priority and motivate every aspect of the community -- schools, churches, businesses, parent and youth groups, the media -- to become involved. The Partnership provides information about prevention strategies from which a community can construct its own plan of action, and helps locate technical assistance and resources to build successful programs.

WHAT SHOULD I DO NEXT?

Write to the National Partnership for help in getting started. If you represent an organization that should belong to the National Partnership, ask for a membership application. Contact: John McGwire, Vice President for State and Local Partnerships, National Partnership, Suite 428, 1110 Vermont Avenue, Washington, D.C., 20005, (202) 429-2940.

Chairman MILLER. Thank you very much.

Dr. Fenton, what is going on at your university, in terms of teaching future physicians how to cope with the problems we are discussing today? How do we deal with what we hear here about some physicians who say that this is a nonmedical problem, or who do not have time in their clinics to deal with a problem which cuts across all socioeconomic lines. A good number of these pregnant women are going to walk right into a private physician's office, and may or may not manifest this problem that is going to occur in their newborn infant.

What is going on in your medical school and others to address this?

Dr. FENTON. I think that——

Chairman MILLER. We always hear about what is not included in the curriculum of medical schools. And they seem to be those items which most widely affect the American population. Nutrition, alcohol, smoking, exercise. These are not included.

Dr. FENTON. I think that far too little is really done to even educate the medical students as to the extent of the problem.

I have yet to question a junior medical student, whom I have not had contact with, who really understood what the problem was for the smoking mother, for instance. Who really understood there was anything more than maybe just the baby will not weigh quite as much.

So, I think that our educational programs, even in the medical school, are very deficient. Now, hopefully, by the time I get done with a student it will have changed. But it is very deficient in really coming down and having a student grapple——

Chairman MILLER. So in the formal curriculum so—speaking from your own experience at your university—there is no formal curriculum to address this problem, and become informed, and to figure out how to work with it?

Dr. FENTON. Ann, do you have some data on that? I have none on the formal curriculum.

Dr. WILSON. Our medical school is focused, primarily on undergraduate medical education, with less emphasis on residencies in pediatrics. But I can speak about programs that include teaching for freshmen, sophomore, junior, and senior students.

In the freshman year, we have a course, Introduction to Human Development which is a part of the Introduction to Clinical Medicine curriculum. This course discusses development from "womb to tomb" or human development across the lifecycle. Although this is an introductory course, and the level of integration with clinical medicine is down the road for the students, we do spend time clearly talking about the prenatal effects of various agents on the developing fetus. We talk about parenting. We talk about the needs of the growing baby to be cared for in a supportive environment, and that this will affect their own future ability to care——

Chairman MILLER. Let me interrupt you. From the moment we walked in here this morning, throughout the testimony, members of this committee have been exposed to a rather high level of trauma, in terms of the impact of this behavior, and our failure to cope with it.

And you can hear it in my voice. I hope you are not telling me that you deal with the effect of drugs and alcohol and smoking in a survey course, when, in fact, we see the impact on hundreds of thousands of newborn infants on a yearly basis. And millions of pregnant women. I hope that is not your answer.

Dr. **Wilson.** No. I am telling you about the beginning of the student's introduction to that problem and that this is at a very early stage in their medical career. I think the impact on the clinical basis comes later in their training. Information about substance abuse is certainly a part of the curriculum, and is integrated into their overall training program from the very beginning.

Chairman **Miller.** Why do we continuously feel, then, that the physicians are not able to either identify the problem, screen the problem, or to cope with it, in terms of their patients? I mean, this is something I have heard the entire time I have spent in public life.

I started way back in the school lunch program being told that the physicians could not identify malnourished children. I am still told that, but it is less prevalent.

What is going on? I mean, in your testimony, you lay out a very bleak picture of a generation and expending numbers of people in a generation who are going to be incapable of functioning. And yet, physicians do not appear to be in a position to deal with it.

And I open this up to the panel at this point to start with.

Dr. **Fenton.** I really—I think you have hit upon an important thing. I think that medical education—and other members of the panel may disagree—is seldom geared toward societal ills. Because nobody knows how to deal with them. It is geared to treatment of very specific illnesses. And we know what to do about those.

But tackling the large problems, which may have a far greater public health effect, are seldom approached with that kind of vigor.

Dr. **Clarren.** Congressman, I think your point is extremely well taken, and absolutely accurate. I think we are not well trained to handle these problems in medicine. I am a teacher at the University of Washington School of Medicine, and I am actively involved in our undergraduate and graduate programs, both in pediatrics as well as across the medical school.

I think the first problem is the compartmentalization of medicine. You treat addicts in psychiatry. You deliver babies in obstetrics. And we care for these damaged children in pediatrics.

I have had obstetricians stand at meetings like this and say with a completely straight face that they had never seen a damaged baby born to an alcoholic mother. And I am sure they believed they were telling the truth. Because they never looked.

And the problems of each of these groups are so foreign to the problems of each of the other groups that they are all paralyzed to really grasp the problem.

The answer will come, not from training doctors in medical schools. The answer, I am sure, will come by a trend in our society to ask the doctors what needs to be done. And through increased pressure from the Government, the popular press, and the public.

Dr. **Fenton.** I did a very brief calculation, if I may?

Chairman **Miller.** Yes.

Dr. **Fenton**. On what the cost might be of preventing, or eliminating 1 day of neonatal care in an intensive care unit.

If we assume that there are approximately 3.6 million children born each year, and let us assume that perhaps as few as 0.1 percent of those might be in that intensive care unit because of some sort of drug or alcohol abuse problem. If we save that child 1 day of hospitalization, on the basis of $1,000 a day in the hospital, that would be a savings of $3.6 million a year.

Chairman **Miller**. The purpose of this hearing is not to point fingers. But the purpose of this hearing is to try to direct public policy to those areas where the investment of some resources will provide a positive return, whether it is education, or intervention, or the combination of both of those. You have addressed activities that are broadly based in the society—drinking and smoking. According to your testimony, they have a direct impact on both outcomes, not for a drug-crazed individual, or people who have lost their ability to function.

But these activities have a severe impact on the outcome of a pregnancy. And clearly one of the areas for education and intervention could be the doctor's office. Some investment in the doctor delivering credible advice, and information, and diagnosis leads could lead to savings. Yet we are told constantly that that training and service is not there.

Maybe that is the subject for another hearing. But I have been through this in occupational disease. You find people saying that if the doctor would just ask them where do they work and what do they work around, maybe we could start to discover what the illness is. Just what is the substance you spend 8 hours a day working on?

But the doctors are not trained to do that. The doctor is not trained to ask. It is a little distressing.

It sounds to me like a second hearing, so we will not burden you with it.

Dr. **Marks**. I would like to respond a little bit to that.

Chairman Miller. I know what we try to build into a public health clinic like a WIC clinic. We try to assemble all the pieces of the puzzle to get this information to the person that is coming in. And the lure is the nutritional package—the food package. But at the same time we try to piggyback a lot of other health-related information to that person. But it starts to appear that for a middle-class person that education is not going on in the doctor's office.

Dr. **Marks**. The——

Chairman **Miller**. Go ahead.

Dr. **Marks**. The issues are complex. I think that teaching is changing a little bit. The medical students that I see have a better sense of it, but they do not know how to incorporate it, how to actually use this in practice.

When you get in practice, you are under a lot of time pressure. You are not paid for the time spent counseling. You are not paid for doing it, but there are places you can refer them to.

You are paid if you use an ultrasound in your office. You are paid for drawing certain blood tests.

And then finally, I think the physicians do not realize, and do not see that this infant was born small due to the fact that women smoke.

It is very common for physicians to be discouraged. Certainly we know from surveys that they are discouraged in their ability to counsel people to make them change their behaviors. And yet, when you talk to patients or when you talk to the public, they say that a physician's advice is one of the most important things. Patients may not make the decision at that time, but they may think about it. They may notice there are others quitting, and that kind of thing reinforces the physician's counseling.

The issue regarding public media such as women's magazines is that the largest advertisers, as far as dollars, are tobacco companies and makers of alcoholic beverages. As a result very few magazines accept articles regarding the health effects of smoking and alcohol.

Dr. CLARREN. I think that is just the essence of the problem. Which is our incredible societal ambivalence.

Physicians are ambivalent. But they are a very small slice of really changing the societal cloth on this issue.

We finally have child abuse laws in this country. We do not have anything like a fetus abuse law. What, exactly, is the difference between a woman who hurts her baby at age 1, by hitting him over the head with a bat, and a woman who is highly abusing one of these agents, and blowing up his brain while she is carrying the child? There is no difference.

But we have no legislation, no societal mandate. No societal consciousness that that is a bad thing for that woman to do. That is the first thing.

The second thing is the incredible conflicting information that women hear. Doctors are a very, very small source of medical information today. There is health education on television, magazines, television, and in this area, it is completely overshadowed by the very sophisticated advertising of the smoking and alcohol industries.

Ms. ARKIN. And even in the physician's office, it is not just the physician. It is also the nurse who may see a woman sitting in the waiting room smoking a cigarette when she is pregnant. So, even though there is maybe a problem with the physician, we need to look at those other people who are seeing the pregnant woman as well, especially WIC staff.

One of the reasons why we started this substance abuse program in our coalition, is that we had so many requests from WIC staff, who said, we see women who clearly are using alcohol, or smoking cigarettes, or using drugs, waiting sometimes very long times in our waiting room. And we have not been trained—we are nutritionists, and we do not know what to do with them.

So, that is another place that we do need to look. These are people who really want to do something. That is why they work for WIC. And yet, they really do not know how, either.

Chairman MILLER. Dr. Clarren, in the testimony earlier, with respect to drugs, there was a suggestion that the adverse impacts can continue after birth. That the drugs show up in the mother's milk. Is that also true in alcohol?

Dr. **Clarren**. Sure. Alcohol will be in the mother's milk in the same concentration it is in her bloodstream. Now that is a much, much smaller concentration than what she took by mouth. And generally, it is not that even a woman who is actively drinking is going to give her baby an enormous amount of alcohol. But it is definitely present. Certainly it can sedate a baby to have breast milk that has alcohol in it.

Chairman **Miller**. What is the response of the physicians and the WIC clinic people to your program, in terms of this kind of information?

Ms. **Arkin**. The response has been very positive. It is just give us more. There is not really enough that you are doing for us. We need more materials. We need more help. It literally is reaching 1,500 physicians—we need to be reaching a lot more people.

Chairman **Miller**. Dr. Clarren, in the alcohol teratogenicity I am not pronouncing that right.

Dr. **Clarren**. Teratogenicity.

Chairman **Miller**. Teratogenicity. What are you talking about there?

Dr. **Clarren**. A couple of things. The word teratogen is what doctors use to define environmental causes of birth defects, as opposed to genetic causes of birth defects. So, a virus, or alcohol, or cigarette, or any of these things that hurts the baby, that is a teratogen.

I should also just comment on the origin of the word. It means, literally, to make a monster. It is only about a 50-year-old term. But it was OK, 50 years ago, to think about children with birth defects as monsters.

I think it is a whole other societal problem. And maybe one of the reasons emotionally, we have had trouble grasping with this. Because there are a lot of emotional and magical implications to birth defects that make the whole issue kind of one that people prefer to avoid.

Chairman **Miller**. Does that also go to the notion of spontaneous abortions, miscarriages, the word teratogen?

Dr. **Clarren**. Yes; those can be teratogenic outcome, sure.

Chairman **Miller**. So will we see that with respect to alcohol?

Dr. **Clarren**. Yes; alcohol increases miscarriage rates rather dramatically. Women who are drinking as little as 1 ounce of absolute alcohol daily increase their miscarriage rate about twofold.

Chairman **Miller**. When you talk to physicians, you get two impressions on that. One notion is a glass of wine a day really is not harmful, which it may not be. But yet, you are also increasing the risk of a miscarriage, as you just pointed out. So, it is what—it is not harmful generally but it is——

Dr. **Clarren**. It is not harmful—the fetus who aborts.

Chairman **Miller**. So how do you convey that information? How do you accurately do that? What is the primary way?

Dr. **Clarren**. That is why I think we need some very sophisticated marketing analysis. It is the kind of thing that Ms. Arkin was talking about. I do not think we really know how to convincingly explain to people that just because three of their friends had normal babies when they drank a small amount of alcohol, or smoked a few cigarettes, that their baby will necessarily be normal, too.

Chairman **Miller**. I belong to a generation that believes that they all grew up normal. And yet, their parents probably smoked and drank—and a lot of these issues were not publicly discussed, nor did we have the knowledge. We all sort of figured our parents did it, and that is the norm.

Dr. **Clarren**. Right. Think about how smart we would all be——

Chairman **Miller** [continuing]. So I think our generation suffered greatly, as a result. [Laughter.]

So, again, if you are talking to people like myself, who are in a position of policy, who talk to audiences all the time, should the rule really be, if you are pregnant, you do not smoke and you do not drink?

Dr. **Clarren**. Yes.

Dr. **Marks**. Yes.

Chairman **Miller**. And we are quibbling over whether we are talking about one glass of wine, or one beer, or a half a shot of whiskey. That is really not at issue though, is it?

Dr. **Clarren**. No.

Ms. **Arkin**. But what we also have to——

Chairman **Miller**. You have got to keep this interesting.

Ms. **Arkin**. Well, keep it simple, but it is not enough to tell women not to do those things. Because they do also need the help to deal with their own stresses in some other way.

Dr. **Clarren**. Yes.

Ms. **Arkin**. So the answer is not to say do not do it. The answer is to say do not do it, instead, try this. And to say that also to her family, and to the people around her, so that they can encourage her in a positive way, too.

Chairman **Miller**. Suggestions? I mean, what are you doing in the healthy——

Ms. **Arkin**. Well, as you have heard, it is to tell the health care provider what to tell that woman. Try taking a walk, or a warm bath, or whatever. It is to work with the families, and all of us who know pregnant women to say—do not chastise her, but do not offer her a drink. Offer her a club soda, instead.

It is also public education, so that all of us will know about these factors before we become pregnant, and be prepared, as a society, to support these women.

I am still simplifying it, Mr. Miller, because we are talking about middle class women, then, who can deal with their problems in some other way. And I cannot give you an answer for a low-income woman, for whom a problem is so immense that—we are not talking about substituting warm milk for an aspirin. We are talking about real-life problems.

And I do not have an answer for that.

Chairman **Miller**. Dr. Clarren, what you are suggesting, in terms of the impact of alcohol during pregnancy, is that we could be a lot smarter society if we did not do it, I mean in terms of brain development, or development of those children in that particular generation?

Dr. **Clarren**. We are—in our monkey model, where we can—where we have the opportunity to remove the brain and actually measure chemical changes, subtle points, that it would be impossible to diagnose in human beings of any age. We find chemical changes in the brains of monkeys exposed to as little as three drinks once a week.

At this point in time, I have no idea how many IQ points that may make you lose, or how much that predisposes you to degenerative diseases later in life. Or other——

Chairman **Miller**. You do not see the opposite, though?

Dr. **Clarren**. You never see the opposite.

But the point is, that these changes are there, at very low levels of consumption. We do not know how dangerous they are, but they are there. And that means that there is, in fact, no safe level of these drugs.

You can have very, very limited amounts—they are dangerous. More to some fetuses than to most fetuses. But they are dangerous.

Chairman **Miller**. Well, thank you.

Dr. **Marks**. I wanted to add one thing. It is clear that the prevalence of smoking in women increased among those in the early part of the baby boom generation, and among teens. Female smoking is probably continuing to increase—certainly it is increasing among Hispanics.

Probably alcohol consumption by women is also something that was less common, but has become more common in our society. So that it may be not our generation who was at risk but the generation behind us may be at increasing risk.

Chairman **Miller**. That is a good point.

Anything else?

Dr. **Fenton**. I guess I would like to emphasize, if I could, perhaps something that Dr. Clarren said. I do not think it was really spoken to this morning.

I think we have talked a lot about the physical damage, and we have alluded to the emotional damage. But for me, actually in the intensive care unit, I see a certain percentage of kids who are actually physically damaged. And probably some with more physical damage than you can even determine by testing, because it is so subtle.

But the emotional damage to come, once they leave the nursery, is a far larger portion of the iceberg, which then allows the problem to continue, and to be passed on, and to mushroom.

When Dr. Clarren spoke of laws that pertain to fetal abuse, or the lack of laws that pertain to fetal abuse, that would be an area of public policy that would allow at least some action to be taken.

In the State of Arizona, it was possible to take a child out of the home when the mother was a drug addict. If the child had evidence of addiction—withdrawal—it could be shown that the child was already abused and therefore, came under the Child Protective Act, and action could be taken. He did not have to be battered before the child was actually removed.

At some point, with all of the things that we do to keep families together, and to rehabilitate families—at some point a decision has to be made on behalf of that child, to be able to finally and permanently remove them from the—a home which is abusive, or emotionally degrading in some way. So at least the cycle can be interrupted there.

And that is a very difficult social concept, which is not generally advocated by social workers or by others. But I see it as an important step to break that cycle.

Chairman **Miller**. You are right. It is going to be tough, dealing with federal laws on abortion, and adoption and foster care. Trying to break the poverty or abuse cycle, and to get society to understand it in some cases, and to understand that is in the best interest of everybody. Sometimes to do a very difficult thing.

What do we do, in terms of the other influences, just quickly. Jenny's ended up spending time with an alcoholic man. We have been told in previous hearings that women who are married to alcoholic husbands will drink more than other women.

How do you address that one? How do you—in terms of public policy? Perhaps your coalition is also addressing this issue, Ms. Arkin?

Ms. **Arkin**. I do not think you address it in any one way. What we will probably all say is that in that case, Mr. Miller, you are talking about what is happening in a home. We have also talked about what is happening in a medical care facility. We are talking about settings all through the community.

And from a public policy point of view, if we can address the acceptance of substance use during pregnancy, and generally, in the society, in all sectors of our society. That is, when you are questioning not just NIH—this morning someone turned to NIH. But when you are questioning any Federal agency, you may consider whether there is a role for substance abuse policy in that area.

It is not just a health problem. It is a problem with our schools, our court system, our community, our businesses are affected. And I think that the point is to—in whatever situation you are in, to think, is this a place where substance use has some—well, some effect.

And I think you will find that almost anywhere.

Chairman **Miller**. Thank you. Thank you very much for your time and your expertise.

With that, the committee will stand adjourned.

[Whereupon, at 12:47 p.m., the committee was adjourned.]

[Material submitted for inclusion in the record follows:]

Prepared Statement of Melvin E. Jenkins, M.D., Professor and Chairman, Department of Pediatrics and Child Health, Howard University College of Medicine, Washington, DC

BACKGROUND

Of the approximately 20,000 infants born in the District of Columbia each year, fifty percent are born to residents of the city. Many of these infants are born at Howard University Hospital and the District of Columbia General Hospital. Each of these hospitals has about 2,000 deliveries per year.

At each of these hospitals, 45 percent of the pregnancies of mothers presenting to the delivery room can be placed in the category of high-risk by virtue of age, each of prenatal care, explosure of the infant to maternal use of drugs, alcohol and tobacco, or medical cordition previously diagnosed.

While prematurity/low birth weight is, of itself, a significant contributor to neonatal morbidity and mortality, the added burden of drug, alcohol and/or tobacco exposure often causes these infants to require longer hospitalizations. The additional burden placed on a child's development when he returns to a home environment, where particularily drug and alcohol are abused, is beyond the scope of this commentary.

THE PROBLEM

Babies do not come to the NICU nursery with one factor causing their illness; these infants have many problems, their families have many problems.

In 1985 Howard University Hospital and the District of Columbia General Hospital nurseries treated approximately 3000 newborns. Of these a large percentage had evidence of maternal exposure to alcohol. In other infants a history of maternal consumption of alcohol was obtained. 5-10 percent had symptoms of drug withdrawal. Other infants had a history of maternal drug use.

Our adolescent units treats many teenagers each year for drug-related illnesses, including PCP use. Numerous, other teenagers are seen each year with alcohol related health problems and countless adolescent girls and boys are treated for STD. Therefore, the young adult population, soon to be or already parents, is a group where drug and alcohol abuse are prevalent and a group whose lack of awareness of health care puts pregnancies at risk from infection as well.

WHAT IS BEING DONE

Many professionals are involved in the care of the mother and her baby once she identifies herself as pregnant and some effective programs are in place at the national/local/institutional level involving public and private sector. Healthy Mothers Healthy Babies is a good example of this effort as is the Adolescent Infant Development Program at Howard University Hospital.

What presently cannot be done is to identify a pregnant mother who does not come to 1) a physician, 2) a hospital, 3) a social worker, 4) a supplemental food program and 5) a knowledgeable friend. In other words if a mother wants to remain unknown, she can. Many women who are abusers of alcohol, drugs and/or tobacco will want to hide or deny their pregnancy.

WHAT OUGHT TO BE DONE

Public education will be the keystone to making sure that the majority of parents and parents-to-be are aware of the steps to take to avoid high risks in pregnancy. Parents need also to know that nothing guarantees a perfect baby, but many known teratogens can be avoided. Parents-to-be should also be knowledgeable in child development so that post-natal growth and development will be optimal for sttistics indicate that deaths after the first month of life contribute to the overall neonatal mortal, by rate in a significant fashion.

Education of professionals will help them to identify those high risk parents and parents-to-be who can benefit from help introduced at any point in the family life cycle.

There, remains, however, a small but significant group who will not be reached by these efforts, both before and after the birth of a baby. These parent-infant groups are particularily vulnerable to the physical and psychological harms of drug, alcohol and tobacco abuse. For this group there must be concerted out reach efforts. This requires the most valuable health care resource we have, caring people. The efforts in place at present are so very limited and overburdened that resources after arrive too late to significantly change the outcome for the child and the financial cost to the taxpayer. Prevention depends on reaching the group very early, at a time when who is high risk cannot be known by urine testing or psychological tests. It requires that education and out reach begin in the elementary schools and that these efforts be pursued vigorously throughout the public school years.

Certainly our care and support of infants born to mothers who abuse drugs, alcohol and tobacco must continue with out reach and education and loving commitment of health care resoruces. However, our hope lies in preventing the abuse of thes substances by young people and preventing pregnancy in those who do abuse them.

Research support for efforts to treat and prevent conditions associate with parental addiction must continue because in this lies our best hope for improving the physical outcome for infants born to mothers who abuse alcohol, tobacco and drugs.

ADDENDUM TO HEARING PROCEEDINGS - A. L. WILSON, Ph.D.

I would like to submit to the written record of this hearing a very brief review of the integrated curriculum on Substance Abuse, which is taught at the University of South Dakota School of Medicine. Some of this material was presented in response to questions of my panel, but I would like to more fully describe our curriculum.

A coordinated effort has been made to provide students, in their first two years of medical school, with a firm foundation on the adverse physical, psychological, and social effects of Substance Abuse and its treatment. This material is presented to students through lectures on the epidemiology of Substance Abuse, the prenatal effects of drugs, alcohol, and tobacco on fetal growth and development, women and alcohol, treatment modalities, differential diagnoses, and the disease process. The students attend seminars with recovering alcoholics, drug addicts, and impaired physicians. They also participate in small group discussions, which focus upon their personal attitudes toward Substance Abuse. As part of their course on physical diagnosis, students learn to include Substance Abuse as part of routine history taking. This material is then reinforced for students when they attend specifically focused floor rounds on alcoholism and during three half-day visits to treatment centers where they are supervised in doing patient histories.

During the students' third and fourth years, information about Substance Abuse is clinically presented to them in their Psychiatry, Internal Medicine, Pediatrics, Obstetrics and Family Medicine clerkships. Perhaps of greatest importance is the students' observations of how practicing physicians incorporate this concern into their routine clinical care. While this is a most difficult experience to assure in their education, efforts are being made by the University of South Dakota School of Medicine to provide continuing medical and community education on substance abuse to practicing physicians throughout our state.